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ABSTRACT

Six papers are presented. The topics are: (1) the limits of cost-benefit analysis as a guide to priority-setting in rehabilitation; (2) public policy towards disability; (3) benefit and costs of the federal-state vocational rehabilitation program; (4) social issues in rehabilitation; (5) public expectations; (6) consumer perspectives; and (7) critical issues facing the health care system. (BB)

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Science and Technology in the Service of the Physically Handicapped

Volume II
Supporting Papers

Committee on National Needs for the Rehabilitation of the Physically Handicapped

Division of Medical Sciences

Assembly of Life Sciences

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Volume 2

SUPPORTING PAPERS

Committee on National Needs for the Rehabilitation
of the Physically Handicapped
Division of Medical Sciences
Assembly of Life Sciences
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Washington, D.C. 1976

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VOLUME 2

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THE LIMITS OF COST-BENEFIT ANALYSIS AS A GUIDE TO PRIORITY-SETTING IN REHABILITATION

by

John H. Noble, Jr., Ph.D.*

Director of Research and Policy Analysis
for Social Services/Human Development
Office of the Assistant Secretary for
Planning and Evaluation
Department of Health, Education, and Welfare
Washington, D.C.

*The interpretations and conclusions expressed in this paper are the author's and are not intended to represent the position or policy of the Department of Health, Education, and Welfare.

No less than 18 cost-benefit studies of the Federal-State Rehabilitation Program as a whole or its component parts have been published since 1965 (1-18). These studies have been used primarily to win from Federal and State legislatures and budget authorities support for increased program expenditures. In theory, policy-makers and program managers concerned with targeting resources to meet the rehabilitation needs of the nation can rely on this backlog of studies to decide among alternative kinds and amounts of investment. Cost-benefit analysis, after all, is supposed to provide the information necessary to make economically efficient decisions, i.e., those which either maximize social welfare or limit expenditures to no more than the expected value of benefits at the time of investment.

The insufficiency of resources to satisfy every community desire makes choice necessary and forces consideration of priorities not only with respect to which persons to serve but also the kinds of R&D* to support. This paper questions the readiness of cost-benefit analysis to conclude anything about priorities in the field of rehabilitation. It concludes that the state of the art is still extremely crude due to overly simplistic forecasting of the future earnings of rehabilitants, the insufficiencies of data concerning the benefits and costs of rehabilitation, and the extreme sensitivity of the cost-benefit model's results to its untested underlying assumptions. It argues, therefore, against priority setting by reference to intuitively appealing class-specific calculations that might appear to show greater rates of return for investments in some kinds of disabled persons over others, and, a fortiori, against using these calculations as the basis for R&D planning. Finally, it recommends steps to enhance the empirical knowledge base upon which cost-benefit analysis depends for validity.

The Rehabilitation Program

The Federal-State Rehabilitation Program in the U.S. offers grants-in-aid to the States on an 80 percent matching basis to help them meet the costs of providing rehabilitation services to persons whose physical or mental impairments present a substantial handicap to gainful employment. Between the Federal share and the contributions of the States, annual expenditures reached nearly one billion dollars in Fiscal Year 1976.

The program is authorized to provide a broad range of goods and services to eligible applicants: from general counseling to physical and mental restorative services, such as surgery, prosthetic and orthotic appliances, and psychiatric care, to training in vocational schools and institutions of higher education, to income maintenance and transportation while undergoing treatment, to purchase of occupational tools and licenses, to job placement and follow-up services. State agency counselors and their counterparts in agencies provide

*Research and Development

services under contract work with clients to develop an individualized plan which combines the goods and services deemed necessary for the achievement of a specific and mutually agreed upon vocational goal.

Since the Federal-State Rehabilitation Program attempts to combine the technologies of medical care, education, and the social services to achieve explicit outcomes, examination of the state of the art of cost-benefit analysis rehabilitation and its ability to direct priorities offers insight and commentary on the state of the art with respect to human service programs in general. Characteristic of these programs is lack of consensus about the nature of the processes leading to desired outcomes and very often conflicting opinions about appropriate goals and objectives.

The Cost-Benefit Model

Cost-benefit analysis seeks to identify investment projects or decisions which will "maximize the present value of all benefits less that of all costs, subject to specified constraints" (19). Expressed in the language of welfare economics, the objective is to rank alternative investments in order to select those which have potential for yielding the Pareto optimum--an improvement that makes at least one person better off and nobody worse off. In principle, all effects of a project capable of enhancing or detracting from individual well-being should be specified, measured, discounted to present value, and compared. A net social gain results if benefits exceed costs (20).

The British economist, Alan Williams, points out the seven assumptions to which we commit ourselves when we accept the principle that services should be provided only if their benefits outweigh the costs. They are:

(1) services can be separated from one another in a sensible way;

(2) choice among them is possible;

(3) outcomes associated with alternative services can be measured;

(4) values can be placed on these outcomes;

(5) costs of providing each service can be estimated;

(6) costs and benefits can be weighed one against the other; and

(7) we should cease providing those services for which the costs outweigh the benefits (21).

Comparison of the benefits of services with their costs requires answers to two major questions: "Who benefits?" and "Who bears the costs?" With respect to rehabilitation services, the answers reflect at least four points of view:

(1) society as a whole;

(2) individual rehabilitants and their families;

(3) employers of rehabilitants; and

(4) the government and its service providers.

Figure 1 sketches, according to analytic perspective, the benefits and costs attributable to rehabilitation.

Economists have largely adopted the societal perspective, but have been unable to document all the possible social benefits and costs of rehabilitation due to measurement problems and data insufficiencies. Although aware of their possible existence, they avoid evaluation of such possible direct benefits to the disabled as improved capacity for self-care, increased mobility, reduced pain and suffering, and increased satisfaction with life. Also not considered are the possible beneficial effects of rehabilitation on the labor force participation of other family members and on general family functioning. On the other hand, increased homemaker services and other unpaid work often receive an imputed value.

Economists, as a consequence of these measurement problems, have emphasized the impact of rehabilitation investments on the Gross National Product (GNP). More specifically, they define benefits as the lifetime earnings that would have been lost had not rehabilitation been provided to persons who are considered "disabled" (22). As such, rehabilitation benefits represent the expected increase over some lesser amount of earnings that might otherwise have occurred.

The costs of rehabilitation include not only program costs consisting of case service expenditures, administrative and overhead costs, etc., but also the "social" or "opportunity" costs of rehabilitation. These latter costs are defined as "the value of resources that would have been available for other uses had special services not been rendered" (4, p. 227). Estimates of social costs, in the opinion of one of the first economists to apply cost-benefit analysis to rehabilitation, are quite speculative (23).

Data and Assumptions

To estimate the lifetime increase in earnings attributable to rehabilitation, most cost-benefit studies have had to rely on before and after estimates of earnings without benefit of a control group against which to compare what would have actually happened if services had been withheld or had a different set of services been administered. The present value of aggregate benefits (PV) is derived by discounting by some rate of interest (r) expected earnings (EE) occurring over time as a probability function of survival (S), employment (Em), age (A), sex (Sx), race (R), education (Ed), type of impairment (I), recurring disability (D), and average growth in the economy due to increased productivity (G). This can be expressed by the general formula:

Figure 1. Benefits and costs of rehabilitation by analytic perspective

BENEFITS AND COSTS	ANALYTIC PERSPECTIVE			
	Individuals and Families	Employers/ Private Sector	Government	Society
A. Benefits Increases				
1. Earnings				X
a. Net of taxes	X			
b. Taxes			X	
2. Homemaker services	X			X
3. Unpaid work	X			X
4. Satisfaction with life	X			X
5. Earnings of family members				X
a. Net of taxes	X			
b. Taxes			X	
6. Decreased medical, nursing and custodial costs (a + b + c = 1)	aX	bX	cX	X
7. Lower turnover in labor markets		X		X
B. Costs				
1. Case service expenditures (a + b + c = 1)	aX	bX	cX	X
2. Administrative and overhead expenses (a + b = 1)		aX	bX	X
3. Income loss/foregone earnings during program				X
a. Net of taxes	X			
b. Taxes			X	
4. Research, training and facility costs (a + b = 1)		aX	bX	X

$$PV = \sum_{i=1}^{n} \frac{EE_i p(S, Em, A, Sx, R, Ed, I, D, G)}{(1 + r)^i},$$

where

n = retirement age minus age at completion of rehabilitation, and

EE_i = expected earnings in ith year.

The studies actually employ formulas which vary with the number and the complexity of the factors and assumptions they attempt to encompass.

Typically, five principal assumptions are combined with earnings before and after rehabilitation to forecast the future earnings of rehabilitants. One--the annual increase in earnings due to the rising productivity of the workforce--affects positively the earnings growth for each age cohort, while the rest act as depressants. The assumptions affecting the magnitude of future earnings vary considerably from study to study.

Productivity increases are sometimes ignored, but more often considered a fixed or variable factor. When treated as a variable factor, the studies either apply different simple rates to different segments of each cohort's expected worklife or test the effects of different compound rates over the entire span of worklife. One study (6) assumed different compound rates for earnings before and after rehabilitation. Assumptions about unemployment are either ignored, considered a fixed factor, or varied by reference to client characteristics or segment of worklife. Most studies make no assumptions about recurring disability or subsume it under unemployment. All studies but one make use of life tables from one or more sources to obtain age-related mortality rates. Most studies set the age of retirement at 65. The exceptions use either 62, 70, or a variable age dependent on the client's age at time of case closure.

Significant differences in benefit and cost concepts, discount rates, and the populations studied make direct comparison between the 18 studies and their results extremely difficult. Table 1 gives indication of these differences. The populations studied range from single to multi-year clientele of the entire Federal-State Rehabilitation Program in the U.S.; from programs in single States to combinations of two or more single State programs; from single special projects to combinations of several; from all cases accepted for service and both paid and unpaid outcomes to only cases with earnings at closure or with certain kinds of disability; and from universes of clients to samples followed up over varying time periods. One study (13) eschews analysis of any particular data base and instead derives client profiles from a variety of sources.

Table 1. Study population, benefit and cost concepts, discount rates and B/C ratios

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios
1.	R. W. Conley Economics of VR (1965)	Total FSVR Program rehabilitants with earnings, FY 1959-1963 (N = 393,381)	Increased earnings by fiscal year of rehabilitants, excluding homemakers and unpaid family workers	Annual Federal and State VR program costs	4%, 8%	Discount Rate 4% 13.5 - 17.1 8% 9.5 - 12.0
2.	Mars, L. (HEW, 1967)	Total FSVR Program, FY 1966 (N = 203,248)	Increased earnings of (a) rehabilitants; (b) homemakers, valued at $1,832 mean wage for full-time maid in 1964; (c) unpaid family workers valued at $1,990 annual wage; and (d) wage earnings of non-rehabilitants, whose earnings at closure were known	Annual Federal and State VR program costs, excluding costs of R&D, training, facilities, and international program and without adjustment for foregone earnings of clients while undergoing treatment	4%	Wage earners--30.5 Homemakers & unpaid family workers--4.5 Self-employed farmers--0.60 Non-rehabilitants--0.05
3.	R. W. Conley (HEW, 1967)	Total FSVR Program rehabilitants with earnings FY 1958-1966 (N = 957,151)	Same as (1965)	Same as (1965)	Same as (1965)	Discount Rate 4% 10.9 - 14.8 8% 7.6 - 10.4
4.	R. W. Conley Journal of Human Resources (1969)	Total FSVR Program rehabilitants, FY 1958-1967 (N = 1,130,745)	Increased earnings by fiscal year of rehabilitants, excluding homemakers and unpaid family workers	Annual Federal and State VR program costs, adjusted upwards by 42% plus 35% of estimated annual earnings of rehabilitants at closure to reflect full social costs	0, 4%, 8%	Discount Rate 0 7.9 - 10.9 4% 4.8 - 6.7 8% 3.3 - 4.7

Table 1. (Cont.)

Author	Population	Benefits	Costs	Discount Rates	B/C Ratios
5. Statistical Notes (HEW, 1969)	Total FSVR Program and 19 selected groups of clients, FY 1967 (N unspecified)	Increased earnings of (a) rehabilitants; (b) homemakers, valued at (i) zero and (ii) mean earnings of wage earners and self-employed; and (c) unpaid family workers, valued as homemakers in (b)(i) and (ii) above	(a) Direct case service costs; and (b) full costs after adjustments upward of (i) 11.6% for services paid by others and (ii) 67.8% for administration, counseling, and capital outlays	None	Full costs--1.97* Direct service costs and with homemakers and unpaid family workers (a) included--4.35, (b) excluded--3.58 *Strictly speaking, not B/C ratio but ratio of earnings at closure to costs, without a forecast of what the value of these earnings might become if they continue into the future under usual B/C assumptions
6. Wright, Beagles, Butler (1969)	Rehabilitants of Wisconsin DVR Demonstration Project, Wood and Eau Clair Counties, July 1, 1966-June 30, 1968 (N = 988)	Increased earnings of (a) rehabilitants; (b) homemakers, valued at $1,832 mean wage for full-time maid in 1964; and (c) unpaid family workers, valued at $2,883 annual wage	Case service expenditure by disability, plus estimated share of (a) 18% administrative overhead and counselor salaries and (b) costs of program dropouts	4%	County Disability Type / Wood / Eau Clair Physical 23.38 33.48 Emotional 22.24 40.60 Mental Retardation 30.24 17.93 Cultural 69.51 ---
7. Grigg, Holtman, Martin (1969)	Rehabilitants of special VR/PA demonstration projects in 13 States and the District of Columbia, 1963-1967 (N = 1,100)	Increased earnings of rehabilitants, excluding homemakers and persons of whom information on PA expenditures and earnings at closure was lacking, estimated for 72 client groups via regression analysis	Case service expenditures, including maintenance costs (health care, living expenses, and transportation) during the life of the project, allocated to 72 client groups via regression against age, sex, race, education, disability type, PA type and presence of spouse	10%	7.56 - 69.94

Table 1. (Cont.)

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios		
8.	Michigan DVR (1971)	Michigan DVR Rehabilitants, FY 1969, two years after case closure (N = 417)	Increased earnings of (a) rehabilitants, and (b) homemakers and unpaid family workers, valued at 0 to $40 per week, plus decrease in economic dependency (PA payments), minus an adjustment for the value of earnings foregone while undergoing treatment	Case service costs for 5 types of rehabilitants, plus estimated share of (a) expenditures for administration, counselors, and facilities, (b) costs of program dropouts, and (c) repeater costs	6%		Lifetime	Two Years
						Physically Disabled	22.88	2.69
						Mentally Ill	26.31	2.98
						Mentally Retarded	30.43	3.53
						Public Assistance	18.07	2.43
						Workers' Compensation	39.34	4.57
						Homemakers & Unpaid Family Workers	1.17	--
9.	D. M. Bellanto (1971)	Florida DVR clients accepted for services, FY 1969 (N = 13,888)	Increased earnings of (a) rehabilitants, (b) homemakers valued, if single and without dependents at $1.25 for 20 hour work week --otherwise, at same rate for 40 hours; and (c) unpaid family workers valued at $1.25 per hour for 40 hour work week. Benefits estimated via regression analysis for combinations of 10 variables	Case service expenditures, plus estimated share of administrative and counseling costs, allocated via regression analysis for combinations of 10 variables	4%, 10%		Discount	
						Productivity	4%	10%
						0	20.02	9.69
						3%	31.68	13.08

Table 1. (Cont.)

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios
10.	Institute Interdisciplinary Studies (1972)	Minnesota DVR--all closed cases (N = 6,097) and West Virginia DVR--rehabilitants only (N = 6,570), FY 1970	Separate and combined estimates of (a) increased earnings of 56 groups of rehabilitants, defined by disability type, age, and sex, and (b) benefits to the government, resulting from (i) total increase in tax revenues, assumed as twice that of income tax payments alone and (ii) reduced PA payments	Case service expenditures, plus multiplier reflecting (a) administrative and counseling costs, (b) service costs for non-rehabilitants; (c) proportion of costs for recent and future rehabilitants contained in annual program costs	3%	-2.56 - 5.11
11.	R. W. Conley Economics of MR (1973)	Age by sex by retardation level profiles derived from a variety of sources, FY 1970 (N unspecified)	Lifetime earnings for all continuously employed retardates, excluding homemakers, adjusted downward by (a) 20% to reflect expected unemployment after rehabilitation and (b) 50% of remainder to represent earnings portion attributable to VR services	Case service expenditures, plus (a) estimated share of administration and counseling and (b) 50% increase for (i) "repeaters," (ii) costs of services provided by other agencies, (iii) earnings foregone while undergoing rehabilitation, and (iv) prior research, training and facility expenditures	7%	Retardation Level and Sex / Age at Closure 18 - 45 Years Mild (IQ 50-69) Male: 14.2 - 10.7 Female: 8.3 - 5.7 Moderate (IQ 40-49) Male: 2.2 - 1.7 Female: 1.3 - 0.9

10

Table 1. (Cont.)

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios
12.	Berkeley Planning Associates (1973)	Washington DVR rehabilitants, FY 1972 (N = 2,805)	Earnings increase, adjusted downward by 10% to reflect displacement of nondisabled from jobs in high unemployment economy of Washington, of (a) rehabilitants, and (b) output of homemakers and unpaid family workers, estimated as the ratio of unpaid to paid work in sample multiplied by average increase in paid work	Case service expenditures plus estimated share of 7 disability groups in costs of (a) administration and counseling, (b) repeaters, (c) services provided by other agencies, (d) earnings foregone while undergoing rehabilitation, (e) prior research and training, minus (i) carryover costs and (ii) maintenance payments	4%, 7%, 10%	Discount Rate: 4% / 7% / 10% Overall: 15.5 / 11.0 / 8.5 7 Disability Groups: 6.2-21.1 / 4.3-14.8 / 3.3-11.3
13.	National Analysts (1974)	Sample of DVR clients in California, Georgia, Illinois, New Hampshire, and Pennsylvania, FY 67-69 (N = 3,437)	Increased earnings for 10 age by sex groups of rehabilitants, excluding homemakers and unpaid family workers	Average expenditures per case incurred under Sections 2 and 3 of the VR Act and Social Security Trust Funds, plus portion of indirect costs proportionate to direct costs	4%, 8%	Age Range: Under 18–60+ Discount Rate / Overall / Males / Females 4% / 9.8 / .4-17.1 / .6-14.9 8% / 7.1 / .3-11.4 / .5-10.6
14.	M. Berkowits and M. Anderson (1974)	Perth Amboy Diagnostic and Employability Center (PADEC), Aug 1971-July 1973 (N = 671, linear forecasting model; N=645, curvilinear model)	Increased earnings of rehabilitants, excluding homemakers and unpaid family workers, estimated alternatively on basis of (a) wages at time of application (E_1), (b) employment and wage experience of prior year (E_2) and (c) wage experience of prior year with prior year's unemployment rate applied to earnings after rehabilitation in projections of of future earnings (E_3)	Case service expenditures, plus (a) administrative and counseling costs, (b) research and evaluation expenses and (c) foregone earnings of clients while undergoing rehabilitation, allocated to specific groups according to resource use--(i) hours of counseling, (ii) average weeks active at PADEC, and (iii) average cost per case and percentage of cases in each group	4%, 6%, 8%, 10%	Model with 6% Discount Benefit Definition / Linear / Curvilinear E_1 / 53 / 88 E_2 / 16 / -0.06 E_3 / 3 / --

Table 1. (Cont.)

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios
15.	Rand Corp (1974)	FSVR Program hearing or vision impaired rehabilitants, aged 0-21, FY 1970 (N = 9,704)	Increased lifetime earnings of rehabilitants, excluding homemakers and unpaid family workers	Case service expenditures for 24 types of rehabilitants, plus proportionate share of costs of administration, counseling, and establishment and support of facilities and workshops, and adjusted (a) upward (i) 4% for services provided by others, (ii) 22% for repeaters, (iii) 25% for research, training and construction, and (iv) 35% for foregone earnings, and (b) downward (i) 7% for maintenance payments and (ii) 2% for cases carried over the previous years	4%, 6% 8%, 10%	Discount Rate 4% / 7% / 8% / 10% Overall 10.8 / 8.6 / 7.1 / 6.0 24 Disability Groups 4.3-13.6 / 3.5-10.8 / 2.8-8.9 / 2.4-7.5
16.	Abt Assoc. (1974)	Total FSVR Program rehabilitants, FY 1970 (N = 257,364)	Increased earnings of (a) rehabilitants; (b) homemakers, valued as the ratio of productivity of unpaid to paid output (.40); and (c) other unpaid work, valued as 60% of paid work	Case service expenditures, plus estimated share of (a) administration and counseling, (b) repeaters, (c) services by other agencies, (d) earnings foregone while undergoing rehabilitation, (e) prior research training and construction, minus (i) carryover costs and (ii) maintenance payments	0, 7%, 10%	Discount Rate 0 / 7% / 10% Social (all benefits and costs) 27.1 / 10.7 / 8.3 GNP (all costs, but excluding unpaid work) 25.2 / 9.9 / 7.7 Program (all benefits, but only program costs) 36.6 / 14.4 / 11.2

Table 1. (Cont.)

	Author	Population	Benefits	Costs	Discount Rates	B/C Ratios				
							Discount Rate			
							4%	7%	10%	13%
17.	Urban Institute/ Berkeley Planning Association (1975)	10% samples of total FSVR Program rehabilitants, of whom 33.2% in FY 1970 and 30.5% in FY 1972 are classified by reference to primary disability codes as "most severely handicapped" (S), FY 1970 (N = 23,903; 7,939 (S)) and FY 1972 (N = 27,992, 8,530 (S))	Increased earnings and fringe benefits of (a) rehabilitants, (b) work of homemakers and unpaid family workers, valued at replacement cost, (c) wages of other family members freed from care of rehabilitants for paid work minus (d) repeater costs treated as negative benefits spread over 3 years and discounts	Case service expenditures for total and severely handicapped rehabilitants, plus estimated share in costs of administration, counseling, plant and facilities, and adjusted (a) improved (i) 25% for prior research, demonstrations, and training, (ii) 8% for services provided by others, (iii) foregone earnings, (iv) client borne expenses of service plan, and (b) downward (i) 4% for carryover costs and (ii) 7% for maintenance payments	0, 4%, 7%, 10%, 13%	Overall	21.1	14.1	10.3	8.1
						Most Severely Handicapped	12.4	9.1	7.2	5.9
18.	Bureau of Economic Research (1975)	Random sample of FSVR FY 1970 (N = 3,743 rehabilitants, 1,063 unsuccessful closures)	Increased lifetime earnings of male rehabilitants, including unpaid family workers but not homemakers, valued at mean wage of their stratified cohort; benefits estimated via regression analysis for combinations of 10 variables, following Bellante (1971), but projected by reference to shape of dynamized age-earnings profile of rehabilitants, following Conley's formula (1973)	Case service expenditures plus estimated share of the costs of administration, counseling, facilities and workshops plant, equipment, etc., allocated via regression analysis for combinations of 10 variables, following Bellante (1971). Usual adjustments for income transfers, repeaters, carryovers, client opportunity costs, and research and training are omitted on grounds that severe assumptions concerning benefits offset need for them	4%, 8% 10%	Results of 24 models, arising from different linear and curvilinear projection techniques and combinations of assumptions about productivity and discount rates, range from -7.57 (non-white mental retardate, aged 54 or more) to +49.9 (non-white, mental retardate, aged 35-44)				

Benefit and cost concepts vary considerably in scope and operational definition. Some studies restrict the concept of benefit to paid work; others include the increased value of homemaker and unpaid work activities. The lack of consensus about the value of homemaker activity or how to go about measuring it is reflected, not unexpectedly, in diverse methods for estimating this outcome. Imputed values typically flow from an external reference point, such as the wage paid to a full-time maid, or from analysis within the study population of the relationship between paid and unpaid work. Last, important variations are found in the operational definition of "earnings before rehabilitation," which influences the magnitude of the difference between "before" and "after" earnings, and, hence, the inferred earnings increase due to rehabilitation. Wide variations in resultant benefit-cost ratios occur when "earnings before rehabilitation" is operationalized as the earnings during the week prior or at time of acceptance for services rather than as those of the full prior year.

The 18 studies are also distinguishable by whether or not the concept of social costs is applied and how it is operationalized. Only half of the 18 studies make upward adjustments to reflect the full social costs of rehabilitation. Among these, the most generous assumption about full social costs is made by Conley (4), who increases total annual program costs of the national Federal-State Rehabilitation Program by 42 percent and adds 35 percent of estimated annual earnings at closure to represent the earnings foregone by rehabilitants while undergoing treatment. Last, the studies which undertake class-specific calculations vary on the basis of the methods they employ to estimate and allocate administrative, counseling and certain other indirect costs to different kinds of clients. With but one exception, they all assume proportionality between direct case service expenditures and the rest of program costs.

All studies but one discount the future benefits expected to result from investments in rehabilitation to their present value in order to show the opportunity costs of making the investment. Conceivably, government funds invested in rehabilitation could produce a higher return in some alternative use in either the private or public sector. Of course, one major rationale for government investment is to foster beneficial activities whose attraction for a variety of reasons is not sufficient to draw private resources away from more profitable uses (24). The proper choice of the social discount rate is important, nonetheless, because it is believed to influence the balance of investment between the public and private sectors with attendant effects on immediate and future consumption (25). Controversy surrounds the issue and centers on whether or not observable private sector interest rates are appropriate for discounting the net benefits of social investments (26). Pertinent economic theory and procedures for estimating both the private opportunity cost of capital and the rate of social time preference are still quite rudimentary (27). In any event, the 18 studies under discussion apply discount rates, ranging from 0 to 13 percent, and, more often than not, test the sensitivity of their results to alternative rates. Regardless of the rationale of its selection and pitfalls associated with its use, the discount rate chosen tends to dominate: the higher the rate, the lower the present value of future benefits and resultant benefit-cost ratios.

Sensitivity of the Model

In view of these widely differing approaches, one naturally wonders how sensitive the cost-benefit model is to its assumptions. Moreover, are the data undergirding the assumptions sufficiently robust to support inferences about specific kinds of rehabilitants? When all factors influencing an outcome but one are held constant, the effects on the outcome of the one allowed to vary can be estimated. This basic scientific paradigm for causal inference can be applied, in the absence of hard data, to cost-benefit and other simulation models by trying alternative values for one parameter at a time while holding the rest constant in order to test the sensitivity of the model to its assumptions. Table 2 displays the results of the sensitivity analyses undertaken by several of the studies.

The cost-benefit model is quite sensitive to each of its principal assumptions. A three percent increase in assumed productivity can inflate by 50 percent the resultant benefit-cost ratios. One-half of one percent increase in assumed unemployment can produce a downward shift of five percent. Alternatively, assuming 20 percent greater unemployment five years after case closure can diminish the ratio by as much as 50 percent or as little as 25 percent, depending on whether a high or low base line is used for comparison. Lower mortality rates can give rise to ratios 27 to 36 percent greater than what higher rates would yield. Using a longer versus shorter accounting period to define "earnings before rehabilitation" can reduce ratios by 26 to 70 percent. Inflating program costs to reflect full social costs--depending on the size of the adjustment--can lower resultant ratios by 26 to 54 percent. Including unpaid work and/or varying its values relative to that of paid work can increase ratios by 8 to 22 percent. A discount rate of 13 percent can yield a benefit-cost ratio 62 percent less than would a rate of four percent. Last, varying by 25 percent the assumption of how many persons declared "rehabilitated" would have, without services, averaged the Federal minimum wage, can diminish the ratio by 27 to 58 percent --again depending on the base line used for comparison.

Thus, concatenation of overly optimistic or overly pessimistic assumptions can easily give rise to very high or very low benefit-cost ratios. The sensitivity of the cost-benefit model to its assumptions makes clear how critically important it is to have valid information about the long-term impact of rehabilitation on the labor market experience of different kinds of disabled persons. If small changes in assumptions amplify to such large effects on overall benefit-cost ratios, how much more sensitive must be class-specific ratios?

Let us consider the empirical foundations for a couple of the assumptions in order to illustrate the point. First, economists assume that continued technological progress will lead to real economic growth and increased earnings for the general work force. Even occupations without much capacity for higher productivity, such as teaching and hair-styling, are thought to share in the productivity gains of the rest of the economy because, to keep workers in these occupations, more must be paid for their services by the rest of society. And while this is true on the average, wage growth is likely to be uneven among

Table 2. Sensitivity of B/C Ratios to Varied Assumptions

Assumption and Study	Values/Definitions	Resultant B/C Ratios	Percent Difference
A. Productivity Increase			
Averous, Stahl, Cole (28)	-1.5 vs. 2.5% for both "before" and "after" earnings	7.11 - 10.21	+44
Bellante (9)	0 vs. 3%	20.02 - 31.68	+58
B. Employment			
Averous, Stahl, Cole (28)	Rate of Decline: 0.5%	8.07 - 7.63	-5
Rand Corp. (13)	Rate at 5 years:		
	80 vs. 60%	10.80 - 8.10	-25
	60 vs. 40%	8.10 - 5.40	-33
	40 vs. 20%	5.40 - 2.70	-50
Urban Institute/ Berkeley Planning Associates (17)	Rate at 5 years: 80 vs. 60%	9.14 - 6.84	-25

Table 2. (Cont.)

Assumption and Study	Values/Definitions	Resultant B/C Ratios	Percent Difference
C. Mortality			
Averous, Stahl, Cole (28)	Railroad Retirement disability annuitants (high) vs. U.S. population (low)	7.16 - 9.12	+27
Urban Institute/ Berkeley Planning Associates (17)	Railroad Retirement disability annuitants vs. Society of Actuaries estimate	9.14 - 12.40	+36
D. Definition of "earnings before rehabilitation"			
Averous, Stahl, Cole (28)	$900 vs. $1,800	12.01 - 8.77	-27
Berkowitz and Anderson (15)	Earnings at application (E-1) vs. prior year (E-2)	53.00 - 16.00	-70

Table 2. (Cont.)

Assumption and Study	Values/Definitions	Resultant B/C Ratios	Percent Differences
Conley (4)	Earnings for week vs. year prior to acceptance (1964)	16.50 - 12.20	-26
E. Definition of Cost			
Conley (4)	Program vs. Social (1958)	14.20 - 6.60	-54
Berkeley Planning Associates (12)	Program vs. Social	23.70 - 15.50	-35
Abt Assoc. (16)	Program vs. Social	14.40 - 10.70	-26
F. Definition of Output			
Averous, Stahl, Cole (28)	Ratio of value of unpaid to paid work-- 25% vs. 75%	6.56 - 7.55	+15
Statistical Notes (5)	Unpaid work excluded vs. included	3.58 - 4.35	+22

Table 2. (Cont.)

Assumption and Study	Values/Definitions	Resultant B/C Ratios	Percent Differences
Abt Assoc. (16)	Unpaid work excluded vs. included	9.90 - 10.70	+8
G. Discount Rate			
Averous, Stahl, Cole (28)	0 vs. 4%	19.60 - 11.66	-41
	4 vs. 8%	11.66 - 8.07	-31
	8 vs. 12%	8.07 - 6.15	-24
Urban Institute/ Berkeley Planning Associates (17)	0 vs. 4%	43.30 - 21.08	-51
	4 vs. 7%	21.08 - 14.12	-33
	7 vs. 10%	14.12 - 10.34	-27
	10 vs. 13%	10.34 - 8.08	-22
H. Employement Without VR Services			
Rand Corp. (13)	Employed without VR at average of the Federal minimum wage--		
	25 vs. 50%	9.40 - 6.90	-27
	50 vs. 75%	6.90 - 4.30	-38
	75 vs. 100%	4.30 - 1.80	-58

specific classes of workers and dependent on both worker characteristics and local and institutional demand conditions. For this reason, valid class-specific cost-benefit calculations will have to be sensitive to the factors which predict wage changes among low wage earners. For, as shown in Table 3, the vast majority of rehabilitants at case closure fall into the lower end of the wage continuum.

Data from the OEO* Panel Study of Income Dynamics, which show the wage change patterns that apply to male heads versus wives and female heads of household at different wage levels in the general population, tend to support this conclusion. For the period covered, 1967-1971, the GNP grew an average of eight percent per year. Roughly five percent of it was due to inflation and three percent to real growth (29). As indicated in Table 4, significantly more low wage earners experienced a decline in wages or failed to keep up with inflation than did medium to high wage earners. Moreover, behind the profiles for high and low earning males and females lie differently ordered combinations of worker characteristics and local and institutional demand conditions that predict wage changes within each group. Local and institutional demand conditions, for example, are among the four best predictors of wage change for low-earning wives and female heads of households but are much less influential for low-earning male heads.

Second, the empirical foundation for allocating administrative, counseling, and other indirect costs to specific classes of rehabilitants is extremely weak. Every study but one had to make use of available case by case reported expenditures for purchased goods and services under the assumption of proportionality between these and administrative, counseling, and other indirect costs because of the lack of full information about resource use on behalf of individual clients. Biasing of cost allocations thus becomes a real danger. Purchased services can be substituted for those which the rehabilitation agency might otherwise provide directly. There may even be an inverse relationship between counseling time and effort on behalf of clients for whom orthotic and prosthetic devices and/or other goods and services are purchased and their vouchered value.

The one study which had, in addition to expenditures for purchased goods and services, individualized data on case counseling and facility use illustrates the other kind of distortion that can occur. Berkowitz and Anderson (15) isolate a class of clientele ready for job placement. They require no counseling and very little beyond referral. The class-specific benefit-cost ratio for this kind of rehabilitant was 11:1 in contrast to 3.6:1 for the rest. Pooling employment-ready clients with others to form additional classes for evaluation clearly inflates the ratios for these classes. If employment-ready clients are excluded, how much lower would the overall and class-specific ratios appear?

But just as critical as the availability of appropriately disaggregated data is its quality. There is evidence to suggest that reported statistics and their underlying sources are insufficiently reliable to support class-specific cost-benefit calculations. Unverified and incomplete records are a

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Table 3. Wages* at closure for rehabilitants reporting earnings, FY 1970 (N = 3,058)

Wage	Males	Females
≤$3.00	75.0%	91.5%
3.01 - 4.25	16.8%	6.1%
4.26 +	7.7%	1.4%
Missing Data	0.5%	1.0%
Total	100.0%	100.0%

*Assuming 35 hour average work week.

SOURCE: Special tabulation by Ohio State University of 10,000 random sample of all FSVR R-300 closures, FY 1970.

Table 4. Changes in wage rates by level of wage rates in 1969--male heads vs. wives and female heads of households. (Adapted from (31), pp. 156 and 162)

Change	Low Wage Rate (<$3.00)		Medium to High Wage Rate (>$3.00)	
	Male Heads	Wives and Female Heads	Male Heads	Wives and Female Heads
Decreased	19.6%	13.9%	11.7%	4.8%
Increased by less than Inflation (0-4%)	20.7%	24.5%	19.4%	22.6%
Average Increase (5-9%)	19.6%	22.3%	33.9%	38.6%
Greater than Average Increase (10-14%)	17.7%	22.1%	21.5%	20.6%
Substantial Increase (15% or more)	22.4%	17.2%	13.5%	13.3%
Total	100.0%	100.0%	100.0%	100.0%
Average Annual Percentage Change	7.6%	7.8%	7.7%	8.3%

special hazard. Indicative of the possible size of the problem is recent disclosure of the Social Security Administration's inability to verify more than 58.8 percent of State rehabilitation agency reports of 68,000 Disability Insurance beneficiary rehabilitants in Fiscal Years 1967-1974 (30).

Incomplete records in the computerized files of the Federal agency responsible for generating official statistics for the Federal-State Rehabilitation Program can create significant biases. Discarding unuseable records in preparation of class-specific profiles reduced the official count of rehabilitants by 23 percent in a year when the quality of records was relatively good (18). This, plus prima facie evidence of large biasing effects due to missing data on variables used by several investigators to make class-specific calculations, argues against the acceptance of such calculations as the basis for priority-setting (31). Tables 5 and 6 indicate the extent to which bias can arise from missing data on certain key variables.

This leaves a final issue concerned with causal inference. We have observed how sensitive the cost-benefit model is to the definition and values given to "earnings before rehabilitation." In view of this, it is highly unsatisfactory to estimate what would have happened without services on the basis of earnings reported for some period prior to application without comparison to a control group. "Creaming," "quotas," and "head-counting" in the Federal-State Rehabilitation Program offers a very plausible rival explanation for differences in earnings observed before and after rehabilitation (32). These practices appear to promote systematic overstatement of program effects.

When unrealistic quotas force counselors to seek out the "easiest" cases, such as the employment-ready persons described in the Berkowitz-Anderson study, is it not questionable to credit the counselor and his agency fully for the job placement and the stream of earnings that ensues? To the extent that the easiest cases are persons whom "spontaneous remission" and the general processes of healing lead to renewed work activities, is it not reasonable to ask whether the services were actually needed? And to the extent that the easiest cases are discernible and sought out to make the record look good, what is the wisdom of spending scarce resources for this purpose? Only a valid control group will reveal how much of a difference provision of services actually makes (33).

Implications and Recommendations

But beyond these considerations lies the more worrisome issue--should economists, laboring under the burden of the contaminated and "noisy" program data that now exist, undertake class-specific cost-benefit analyses? I think not and for two reasons. First, they are likely to mesmerize themselves into believing their results and, second, there is grave risk that policy makers might believe the believers and set priorities based on misleading evidence. Until welfare, social insurance, and compensation programs provide income to the disabled more nearly commensurate with what they might have received had they been able to work, foreclosing rehabilitation opportunities on the basis of presently realizable knowledge about the benefits and costs of services to specific kinds of people may lead to gross inequities.

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Table 5. Differences in mean case service expenditures in records containing usable versus one percent or greater amounts of missing data on key variables, FY 1970 (N=4806)

Variable	Mean expenditure in records with useable data	Mean Expenditure in records with missing data
Race	$564	$655
Education	$558	$919
Public assistance status	$560	$1,017
Number of dependents	$561	$776
Secondary disabling condition	$578	$403

Table 6. Records containing unusable versus one percent or greater amounts of missing data on key variables, FY 1970

Sources of variation	Degrees of freedom	Between groups mean squares	Within group mean squares	F
Race	1	500,736	836,100	0.60
Education	1	12,392,192	833,639	14.87**
Public assistance status	1	11,333,120	833,846	13.59**
Number of dependents	1	4,499,712	835,270	5.39*
Secondary disabling conditions	1	9,579,952	834,244	11.51**
Within groups	4804			
Total	4805			

* $p<.02$
** $p<.001$

How are we then to proceed? The insufficiency of resources forces choice and assertion of priorities. Yet the knowledge base is too weak to justify decisions. Until the requisite knowledge becomes available, the political process appears to allow one means of escape from the dilemma. The Congress, by virtue of the Rehabilitation Act of 1973 and Amendments of 1974, has placed priority on serving the severely disabled (34,35).

The legislation, inter alia, requires early determination of eligibility for services, individualized written programs of services to be provided, detailed records for evaluation of persons declared ineligible and the reasons for the decision, and continual State-wide studies of the needs of the disabled, including review of the efficacy of the criteria used for selection/rejection. It also requires that the determination of ineligibility be made only after full efforts to develop a vocational goal have failed and the rehabilitation counselor has certified that the applicant is incapable beyond a reasonable doubt of achieving such a goal.

The intent of the legislation is thus for improved economic analysis of rehabilitation benefits and costs--for what, after all, can justify withholding of services but knowledge that their costs outweigh their benefits? Indeed, equitable resolution of the litigation that may someday arise over certification of incapacity to achieve a vocational goal could well depend on more adequate evidence than is now available concerning the benefits of rehabilitation for specific kinds of people. If certification of incapacity established a rebuttable presumption of eligibility for income maintenance under Social Security Disability Insurance or the Supplementary Security Income Program, the potential dollar drain on these funds might accentuate the urgency of the need for better information. Unfortunately, a rebuttable presumption or other such policy coordinating mechanism does not exist, and rejected applicants are left to fend for themselves (36).

In the case of R&D planning, the lack of reliable knowledge about rehabilitation benefits and costs presents special hazards for applied scientists. Ideally, R&D should be directed toward populations and problems wherein the current rehabilitation investment is yielding negative or low rates of return. The goal of technological innovation should be to improve the rate of return. Recourse to the political process, however, as the means of overcoming the knowledge/choice dilemma may not be the most auspicious way to go. Other alternatives are: consumer choice, scientist opinion, administrative fiat, or some combination of these. Except for perhaps consumer choice, some political considerations inevitably enter into each approach and thereby compromise the more preferable decision-making criteria of objectivity and scientific expertise.

My own bias is toward the kind of peer review of scientist opinion which goes beyond review of project proposals and appraisal of progress to assessment of final research products in terms of their scientific worth and practical utility to consumers and practitioners (37). If the results of such end-product reviews are made conspicuous through publication, interested parties--consumers, practitioners, scientists, program administrators, and legislators--can decide for themselves how much to rely on specific research findings and/or new technologies for their own guidance or use. While not by any means flawless,

peer review appears superior to reliance on consumer choice, administrative fiat, or legislative politics as a guide to setting R&D priorities. If carefully managed and subjected to public monitoring, peer review can optimize on objectivity and scientific expertise and minimize potentially counterproductive special interest pleadings.

The state of the art needs substantial upgrading before cost-benefit analysis can be taken seriously as a guide to priority-setting in the field of rehabilitation. To this end, I make the following recommendations.

First, there is need for research to create better instruments for measuring the full range of benefits that may flow from rehabilitation, including homemaker and other unpaid outputs, reduction of functional limitations in activities of daily living, and improved social and psychological well-being.

Second, there is need to improve cost accounting data--most notably with respect to counselors' use of time on behalf of specific kinds of clients. The Berkowitz-Anderson cost-benefit study (15) comes closest to what is desired. Rehabilitation agency administrators and counselors may resist on the grounds that it takes time away from services to clients, but no real progress is possible without breakthrough here.

Third, the entire statistical reporting system, upon which cost-benefit analysis of the Federal-State Rehabilitation Program has depended for validity, stands in need of quality assurance. The quality of data strains the credibility of class-specific cost-benefit calculations.

Fourth, there is need for study of the values which individuals and families place on the potential range of rehabilitation benefits. Such study would help us to understand how to translate into monetary units observed changes in homemaker and other unpaid work outputs and in activities-of-daily-living (ADL) functioning. This might make it possible to combine both market and non-market measures of benefits into a single global measure that could be compared to costs.

Fifth, better mortality information is needed. Conceivably, the Federal Government could develop standardized life tables for all ten of its disability transfer payment programs (38).

Sixth, there is need for a national panel study of disability, paralleling the OEO Panel Study of Income Dynamics. Although expensive, I see no other feasible alternative for obtaining the longitudinal data needed to test the critical assumptions of cost-benefit analysis concerning the labor market experiences of different kinds of disabled persons.

Seventh, there is great need for controlled studies of the comparative benefits and costs of rehabilitation. The Rehabilitation Amendments of 1974, by placing priority on services to the severely disabled, imply that the "creaming" of the easiest cases is no longer acceptable practice within the Federal-State Rehabilitation Program. To the extent that resources for a given fiscal year are insufficient to serve everybody, it seems ethical to

propose comparison of outcomes for immediately accepted versus delayed clients over relatively short time periods. With assurance that services will eventually be provided, applicants might consent to being randomly selected from the queue and to delays of more than one year. It may also be possible by means of experiment to study how consumers would value certain rehabilitation outcomes if given predetermined amounts of money or their equivalent in vouchers to spend as they see fit. Consumer willingness to pay, while an imperfect guide to how much society ought to spend for rehabilitation, would at least identify for policy makers the minimum amount and its preferred uses (39).

Last, it might be strategic for the Federal-State Rehabilitation Program to deemphasize competitive work as its principal objective. An economy with an oversupply of qualified workers places competitive work beyond the reach of many handicapped persons whose need for assistance in achieving improvements in other areas of functioning is a legitimate goal for government action. To the extent that the program maintains too narrow a vocational orientation, the basis for its constituency support may erode; increasing numbers of handicapped persons will appear incapable of achieving a vocational objective. And as the value of wages at case closure fail to offset the work disincentives of higher income and medical coverage available through the Social Security Disability Insurance and Supplemental Security Income programs, legislative and budget authorities may begin to question the wisdom of spending additional sums for vocational rehabilitation (40). In consequence, medical rehabilitationists, caught in the fiscal squeeze yet unable to jettison responsibilities for persons incapable of achieving vocational objectives, may have to turn to other legislative authorities for support of both their service activities and R&D needs.

New legislation will be required if pursuit of non-vocational objectives is to be made an explicit and legitimate goal of the Federal-State Rehabilitation Program. Resistance to such change appears likely in face of traditional understanding of the productive consequences of vocational rehabilitation. Therein lies the dilemma. Perhaps National Health Insurance will permit coverage of the service needs of the most severely handicapped under an expanded definition of health care.

Of course, when all has been said and done to improve the efficiency of investments in rehabilitation, still left--beyond the scope of cost-benefit analysis--are important economic and political issues concerning the distributional effects and equity of these investments. This is nearly virgin territory for economists interested in the field of rehabilitation.

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31. And given the increasing sophistication of the courts in matters of statistical inference, it seems unlikely that priorities based on class-specific estimates would be sustained in litigation involving rejected applicants for services. See Katz, L. Presentation of a confidence interval estimate as evidence in a legal proceeding. Amer. Stat. 29:138-142, 1975.

32. Persons who enroll in rehabilitation and other job training programs do so typically when their earnings have reached an ebb point--lower than both what they were and what they will be. Those who are more motivated and thus more likely to succeed without help are probably among the first to seek services. This is the "cream" that is skimmed by rehabilitation and manpower training agencies in the quest for statistics showing program "success." For discussion of "creaming," "quotas" and "headcounting," see U.S. Congress, Rehabilitation Amendments of 1972. H. Rept. 92-928. Washington, D.C.: U.S. Government Printing Office, March 16, 1972. 36 pp. and U.S. Department of Health, Education, and Welfare. Report of the National Citizens Advisory Committee on Vocational Rehabilitation to the Secretary of Health, Education, and Welfare. Washington, D.C.: U.S. Government Printing Office, June 26, 1968. 115 pp.

33. Even then, the so-called "displacement" effect may complicate interpretation of a positive benefit-cost ratio in presence of a valid control group. In an employment market where available jobs are fewer than the number of unemployed, simply providing preferential access to jobs for some may result in their gain to the detriment of others with equal or higher skills. While it is not clear that displacement effects can ever be filtered out by means of an experiment, nonetheless, comparison of persons who receive rehabilitation services--with and without direct job placement--would clarify the relationship between benefits and the components of treatment. It is possible that the wage benefits of rehabilitation are more the result of preferential access to jobs than due to the provision of other, possibly more expensive services. For discussion of displacement effects in manpower training programs, see Sewell, D.O. In G.G. Somers and W.D. Woods, Eds. Cost-Benefit Analysis of Manpower Programs, pp. 160-169. Kingston, Canada: Queens University, Industrial Relations Centre, 1969.

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PUBLIC POLICY TOWARDS DISABILITY--THE NUMBERS, THE PROGRAMS, AND SOME ECONOMIC PROBLEMS

by

Monroe Berkowitz, Ph.D.*

Professor of Economics
Director of the Disability and Health
Economics Research Section
Rutgers University
New Brunswick, New Jersey

*The interpretations and conclusions expressed in this paper are the author's and are not intended to represent the position or policy of any institution or agency.

This paper is based on ongoing research conducted at Rutgers University. Portions of this research have appeared in the "Economic Concerns of the Handicapped," a background issue paper prepared for the Task Force on Economic Concerns, White House Conference on Handicapped Individuals, by Monroe Berkowitz, Jeffrey Rubin, and John D. Worrall; and in An Evaluation of the Structure and Functions of Disability Programs, Year I Summary Report, OEO Grant No. 009-P-20-2-74/1 (New Brunswick, N.J.: Rutgers University, Bureau of Economic Research, Disability and Health Economics Research, 1975); and in Monroe Berkowitz, William G. Johnson, and Edward H. Murphy, Public Policy Toward Disability (New York: Praeger Publishers, 1976). The author is indebted to his colleagues at the Bureau of Economic Research, Disability and Health Economics Research, particularly John D. Worrall and Jeffrey Rubin, but only he is responsible for the views and criticisms expressed in the paper.

Definition and demography are discussed in this paper and also in Part II of the Committee's report. This paper discusses cost-benefit analysis briefly. The preceding paper by John H. Noble, Jr. deals with this subject more extensively and more technically.

Introduction

The Committee's charge is to assess the nation's specific needs with respect to the application of science and technology to aid the physically handicapped, to formulate a plan of action to meet those needs and to delineate the most effective role for the NAS/NRC in servicing the nation's needs in this area.

This paper argues that such an assessment requires an understanding about who the target group is, the number in the group, the existing benefits and services designed to aid them. In general, this paper is concerned with an analysis of public policy towards disability, largely from an economics point of view. Conscious of the fact that resources are scarce, we inquire as to how these have been allocated to the disabled and examine some problems with this allocation process.

We begin the paper with an analysis of some conceptual problems which plague anyone who wants to inquire into problems of the physically handicapped and the disabled. The definitional and conceptual section is followed by estimates of the number of people in the population who fall within the disabled category.

Next, we survey briefly the types of services and programs that are available to help serve the needs of the disabled. Emphasis is largely in the public sector. Presumably, if what already exists is adequate, there would be no need for further inquiry. Although we make no definitive judgment about this fundamental question, we do examine the ways in which these programs can be evaluated with attention to their efficiency, equity, and adequacy.

In the last section, we pose some problems. Our thesis is that disability will increasingly come to be recognized as a public problem, and it will increasingly be necessary for advocates of more resources for the disabled to be able to justify their position. In this paper, we stop short of definitive programmatic types of recommendations, but suggest areas that must be explored and policy questions that must be answered as we seek to meet the nation's needs with respect to the application of science, technology, and other resources to aid the physically handicapped.

Definition and Concepts

To the person confined to a wheel chair or unable to walk without crutches, the term handicapped is a real and ever-present fact. He may need no elaborate definitions to convince him of his state, and he may be impatient with papers that begin by delving into the arcane differences among concepts relating to the physically handicapped.

Yet, he and his more able-bodied colleagues face a world ruled by definitions. The definitional barriers which prevent him from enrolling

in a program may be every bit as real as the architectural barriers which prevent him from entering a building. At times it appears that we all live in a "Catch-22" world where the same person is judged too disabled to receive rehabilitation services from one program and not disabled enough to receive benefits from another. If programs cannot agree on a single concept of the handicapped or the disabled, it should not be surprising to see the same cloudiness prevail as we carve out concepts for purposes of counting the disabled or listing their characteristics.

Basic problems arise only as we seek to count people or determine eligibility for services, benefits, or perhaps merely rights to a special parking place. It is clear that if I interfere with no one, if I do not offend or threaten anyone by my presence, nor ask sustenance from anyone, then whether I consider myself handicapped or not is a private matter. My demand for prosthetic or orthotic devices, if expressed in the private market, depends only on my perception of a need, buttressed by the money to purchase the apparatus. The problems arise only when I depart from the private market and seek eligibility for admission to a service or receipt of a benefit which is conditioned upon my establishing membership in a particular group.

As we classify persons into groups, it may be vitally necessary to distinguish among persons with a physical impairment, a functional limitation and a disability. In this paper I view disability as the end result of a series of circumstances culminating in an inability to perform any of the major life functions. The process usually begins with a state of active pathology, associated with the mobilization of defenses and coping mechanisms. The state of active pathology may be the result of the onset of the disease, infections, metabolic imbalances, degenerative disease process, trauma, or other etiology.* A pathological condition involves the interruption of normal bodily processes and also, at the same time, the efforts of the organism to restore a normal state of existence.

Once a state of active pathology is arrested, or eliminated, the individual may be or may not be left with an impairment, a physiological, anatomical, or mental loss, or other anomaly, or both. Every pathology involves an impairment, but not every impairment involves pathology.

Our concern ultimately is with disability, and the most direct way that impairments contribute to disability is through the functional limitations they affect. The most common way we have to get at these functional limitations is to examine the ability of the person to walk, lift, stoop, carry weights, or for his sensory functions, his ability to see, hear, or speak. Limitations in functions, however, can be manifested at various levels, and one could speak of limitations in functions at the levels of molecules, cells, tissues, organs, regions, systems as well as the organism as a whole.

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* The conceptual distinctions as set forth in this paper have been expanded by a number of people over the years. Prominently identified with these distinctions is Saad Z. Nagi (1,2). Many of these same ideas have also been identified with the work Lawrence D. Haber did for the Social Security Administration (3).

People with functional limitations may or may not end up as being disabled, in the sense of an inability or limitation in performing roles and tasks expected of that individual within a social environment. Examples of the functionally limited and impaired persons who are not disabled are commonplace. One man confined to a wheelchair ends up on the Public Assistance rolls and another becomes the President of the United States. People with a wide range of impairments are participating in the labor force; others with the same limitations are unable to work.

To explain which impaired person will be disabled and which will not requires information on three sets of variables in addition to his impairment and functional limitations. The first is information about that person's native characteristics such as age, race, and sex. The second has to do with a person's acquired characteristics such as education, training, habits of work and general attitudes, some of which may be products of past investments in that person's stock of human capital. The third set requires information about the economic environment and the labor market in which that person seeks employment. Thus, it is his physical condition, his characteristics, both acquired and given, and the external factors of the labor market which will determine whether or not he is disabled.

Exactly the same analysis is required in cases of school children whose limitation in role function is not that of work, but of attending school or playing. And for those who would not normally participate in the labor force, we can substitute whatever types of activity is normally expected of them.

The causes of disability then are multiple--a matter that plagues administrators of disability insurance programs, and those who seek to determine eligibility for any program in which physical disability becomes an entrance prerequisite. It does not make any difference which names we attach to these concepts, it would be sufficient if we had agreement about the existence of these different concepts. The term handicapped, for example, has been used in the same way that we use the term disability.

Nagi maintains the term handicapped emerged during the early development of rehabilitation counseling in an attempt to distinguish medical entities which constitute the professional domain of the physician from the nonmedical entities which were to become the domain of rehabilitation(2). However, as he points out, disability is surely not a medical phenomenon, and the term handicapped has never been operationally defined in a way that allows an assessment of what specifically is designated, although sometimes it is viewed in terms of disadvantage. Because of the confusion surrounding the term, many social scientists who have written about the problems of disability would prefer not to use it at all on the grounds that it has no operational meaning and should not be used as a level for functional limitation. Yet, we are faced with the fact the Committee's charge is to assess the nation's needs to aid the physically handicapped. Also, the forthcoming White House Conference in this area has been denominated as the White House Conference

on Handicapped Individuals. The vagueness attached to this term may be an advantage in dealing with a broad Committee charge or a loosely structured conference. It will not do, however, when it comes to a decision about measurement or program eligibility.

We may summarize a complex and almost intractable problem. We note that disability is defined as the inability to perform a role which is expected of the person, and it occurs when that person has a particular impairment or functional limitation which when combined with his other native and acquired characteristics and external forces result in his inability to work, play, recreate, keep house, go to school, or whatever his usual, accustomed and expected function is. It is obvious then that not all impaired or functionally limited persons are disabled, and we take it that the primary function of rehabilitation is to eliminate disability, even though it may not be able to eliminate the underlying impairment or functional limitation.

Counting the Numbers of Disabled

If one adds to the conceptual problems the dimensional ones of severity, it is easy to understand how counts of the number of the disabled can vary. Our probable best sources of information are the periodic Surveys of Disabled Adults (SDA) conducted by the Social Security Administration that depend upon the response of people who are asked to evaluate their own condition. The SDA definition of disability is a limitation in the kind or amount of work, including housework, which lasts six months or longer. Persons who are unable to work, or who are unable to work regularly, are classified as severely disabled. Those defined as being able to work regularly, but unable to work at the job held prior to onset or unable to work full-time are occupationally disabled, and lastly, there are those with secondary work-limitations defined as able to work full-time regularly and at the same work but with limitations in the amount or kind of work they can perform.

Reliable data are available for 1966 (4) and preliminary data for 1972 (5). In 1966, 17.[illegible] million noninstitutionalized persons or about 17.2% of the population between the ages of 18 and 64 were disabled for longer than six months. The severely disabled, however, account for about 6.1 million persons, or 5.9% of the population, the occupationally disabled, about 5 million persons, or 4.9% of the population; and those with secondary limitations were counted as 6.6 million persons or 6.4% of the population. Preliminarily, the 1972 survey counted 7.7 million people severely disabled, 3.5 million people occupationally disabled and 4.4 million persons as having secondary work limitations.

As might be expected, the disabled fare significantly worse than the nondisabled in the labor force. They tend to work shorter hours, they tend to be disproportionately represented among service workers, laborers, and farmers, and comprise more than a third of all private household workers. The weekly wage for severely disabled men tends to be only two-thirds of the average wage with the ratio for females even lower. Most importantly, the

disabled represent a significant share of all persons ages 20 through 64 not in the labor force and possibly more than two-thirds of all working age males not working or looking for work. Unemployment rates tend to be higher among the disabled, and severely disabled males account for more than half of those who did not work during 1971.

Census Data

Another source of information about the disabled comes from the United States Census (6). Of the 1970 U.S. population ages 18 to 64, numbering 112,289,642, there were 11,022,045 persons (or 9.8% of the population) with work disabilities lasting six months or more. The total included 5.8 million men, 10.7% of the men in the noninstitutionalized population in these age groups, and 5.2 million women or 9% of the population. Both these absolute numbers and percentage estimates are considerably less than those reported in the SDA. However, the differences are not great when only the totally disabled are considered.

Age and Disability

No matter which data source is used, the relationship between age and disability is apparent. In the SDA, which reports 17.2% of the noninstitutionalized population ages 18 to 64 as disabled, the youngest age group (those between 18 and 34) have 7.8% disabled, whereas the oldest group (ages 60 to 64) report 42.2% with some disability (7). The 1970 Census reports quite different percentages of the population disabled at each age group, but the age-disability relationship is similar to that of the SDA. In the Census, as in the SDA, the oldest age group shows a percentage rate about five times the youngest when all the disabled are considered, and ten times when only the severely disabled are in question.

There are several obvious reasons for the relationship between disability and age. At the ever-present risk of oversimplification, we can note the following:

1. Health impairments increase in prevalence with age. The cumulative effect of environmental stress and chronic disease contributes to the impairment of physiological capacity for maintenance and regeneration. Personality and cognitive changes may occur in conjunction with organic and functional impairments (8).

2. Work requirements change over time. An older worker's skill may become obsolescent, a factor which may be particularly hard for him to overcome once he becomes unemployed for any reason whatsoever. Pension systems may afford some workers a way out of the world of work by early retirement, and at the same time, these systems may prevent others from being hired. An employer's willingness to hire may be related to the age of the worker, especially if extensive training is required as a prerequisite for performance

on the job (9). The period of time in which the investment in human capital may be amortized is necessarily smaller, the older the worker.

3. Family obligations change over time. A worker's expenses and assets change over the life cycle and his eligibility for alternative types of transfer payments may open up as he grows older. At the same time, his mobility may be lessened. After age 60, the combination of disability, retirement, and dependent's benefits offer a much broader range of income maintenance alternatives to the population ages 60 to 64 than to younger adults.

It is, however, at the ages of 62 to 64 when the proportion of the disabled receiving benefits from the public income maintenance program increases sharply (7). Four-fifths of the men receiving early retirement benefits were disabled, and more than a third were severely disabled. It appears that Social Security's early retirement provisions function as an intermediate disability program paying lower benefits to those unwilling to pay the price of application to the Social Security Disability Insurance Program, unable to qualify, or perhaps even unaware of this option.

4. In examining prevalence data, which is all that the SDA and Census surveys provide, we expect the percentage of persons disabled in the older age group to be greater than the younger age groups because of a natural aging process. The number of persons disabled in any age group is made up of those disabled at an earlier age who survived to their current age, plus those who became disabled at their current age. Obviously, the total excludes those who died or recovered from their disability. So long as the exits from the disability category by death or recovery are fewer than the additions, the total number is bound to swell as age increases. In this respect, improvements in medical care are just as likely to increase the number of disabled as to decrease it. To the extent that mortality is reduced faster than illnesses or accidents are prevented, or their effects ameliorated, the ranks of the disabled will tend to swell.

Age at Onset of Disability

The consequences of disability for the individual are influenced by his age at the onset of disability. A person permanently disabled early in life may never have the opportunity to invest in education or training as a career. A person disabled in his 60's may regard his condition as an acceptable reason for early retirement. As noted above, if the incidence of permanent disability was the same in all age groups, and if the life expectancy for the permanently disabled was comparable to that for the normal population, then the aging effect alone should account for the increasing proportion of the population disabled in the older groups. But accurate incidence data require better information than is now available on date of onset and duration of disability.

At the time of the SDA survey in 1966, the median age of the disabled was 50 years, with 80% of the people reporting that they had been disabled

for more than two years. The median number of years a person had been disabled was eight. Again, at the risk of great oversimplification, and with emphasis on the fact that we are dependent upon a single survey, we can consider the pool of disabled as being fed from three sources.

First is the group of the congenitally disabled and those disabled in early childhood. These are persons with developmental disabilities such as cerebral palsy, epilepsy and mental retardation. Among the SDA disabled population, 17.5% stated that their condition began before the age of 18; and 15.3% that their work limitation began before they turned 18. A greater proportion of those disabled in childhood have respiratory, mental, nervous system, and visual disorders than the disabled with later onset dates. Much of the mental disorder of those disabled in childhood is due to retardation and much of the nervous system disorder, to epilepsy and paralysis (10).

A second stream joins the ranks of the disabled in the prime of their life. Although the median age of all disabled in the survey was 35, nearly one-third noted that their date of onset was between ages 18 and 34.

A larger proportion of those with onset of disability between ages 18 and 34 have musculoskeletal disorders than those with onset of disability at other stages in the life cycle. Many of these disorders may be due to injuries and accidents; a smaller number, to the diseases which are most prevalent at an earlier and a later age (10).

A third stream joins the ranks in the upper age groups. Here we see a growing proportion of the degenerative disorders related to aging. About 41.6% of the group listed 35 to 54 as the age at onset, and an additional 8.9%, 55 to 64. The older the group, the greater the number that reported disorders due to cardiovascular conditions. Among the older disabled, those with onset of disability before age 55 cited heart trouble and high blood pressure as their primary impairment less often than did persons of the same age with later onset of disability.

The later the age at onset of disability, the more likely that the disabled person will leave full-time employment. Again, it is difficult to know whether this is because of the greater severity of progressive diseases and reduced functional capacity related to age, or the availability of early retirement provisions.

Epidemiological Factors and Disability

The SDA collected data on the so-called major disabling conditions which respondents claimed to be primarily responsible for their work limitations. It was left to the individual respondent to designate the condition on the basis of his own experience and the medical information available to him. Musculoskeletal disorders (diseases of the bone and organs of movement) and circulatory disorders account for more than one-half of the major disabling

conditions reported. If we add to these conditions the next most frequent group, allergic and endocrine metabolic disorders, we account for two-thirds of the major disabling conditions (11).

The relative importance of these conditions does not change substantially when we examine them according to degree of disability. Mental and nervous disorders and neoplasms are somewhat more frequent among the severely disabled than among the partially disabled. In general, however, there appears to be no meaningful relationship between the type of condition and the severity of disability.

As already noted, the disability rate, based upon prevalence of major disabling conditions for each thousand persons in the noninstitutionalized population ages 18 to 64, varies directly with age. The rates for circulatory and respiratory disorders, however, increase proportionally more than the total disability rate. Musculoskeletal and digestive systems disorders increase at about the same rate as the total disability rate, whereas allergic and related disorders and mental disorders increase at less than the average rate.

The conditions which come to national prominence and which cause great concern because of mortality factors are not prominent as factors contributing to disability. Musculoskeletal disorders are greater factors in the prevalence of disability than either cancer or stroke, although, of course, musculoskeletal disorders rarely appear as the cause of death.

We emphasize that an understanding of any individual's disability requires knowledge of factors other than his stated medical condition. It is worthwhile, however, to identify the medical conditions which are linked statistically to disability. The conditions which we have cited do not rank as major killers and do not command a large share of the public's funds or the public's attention. Just as the common cold and respiratory illness have been identified as the major cause of short term illness, so it is the back injury, or other musculoskeletal defect, which emerges as a major cause of disability. A recognition of this fact is part of an enlightened public attitude toward the problem of disability.

Problems in Counting the Disabled

The exact number of disabled found in any survey is dependent upon the questions asked and the definitions used. By concentrating on the age group 18-64, we have eliminated some of the more difficult problems of identifying the disabled children and the disabled aged. Despite this restricted focus on the productive age group, however, certain problems arise with the survey findings.

We have said that the assumption which underlies most of the surveys is that disability is a "health-related inability to work." The surveys take as their point of departure the vocational aspect of this disability formula, asking respondents whether they experience any limitations in the performance of work. Once such a limitation is ascertained, the questionnaire usually invites the respondent to trace the limitation to a physical impairment.

This approach to disability has certain weaknesses. The duration and degree of work limitations are variable and do not readily lend themselves to exact measurement. We are not confronted with an "either-or" choice, but with a continuum of possibilities. A person may maintain that his condition absolutely prevents any work whatsoever, or that it limits his hours of work per day, the number of days per week, the regularity of his attendance, or the type of work he can do. Obviously, the findings of the surveys which employ this approach will differ depending upon where each sets the dividing lines between the disability categories. We might infer that there is no ideal way to ask the questions or to classify the answers, and that the discrepancies are inherent in the survey approach. This suggests, in turn, that the relationship between the individual's physical condition and activity limitations is less accessible to documentation, and in general, more complex, than is apparent at first glance.

There is one further difficulty with surveys which assess the prevalence of disability; looking at a group of disabled at one moment in time cannot convey the dynamics of the situation. An example will clarify the problem. The fact that there are a good many more older persons than younger persons disabled is due in part to the increased vulnerability of the older person to disease. However, the aging process, [illegible]cumulative effect which takes place over time, also contributes significantly to the prevalence of disability among older individuals. In an era of medical advances, the same factors which promote lowered mortality may increase disability rates among the older survivors (12).

The Workers' Disability Income System - An Introduction

We have seen that the national surveys arrived at different assessments of the prevalence of disability. This disagreement about the magnitude of the problem is matched by the disagreement about the best way to contend with the problem. Several strategies currently exist to deal with this aspect of disability. In this section, we will consider programs designed to compensate for the income loss of the disabled, and look briefly at the government's rehabilitation program and its legislative efforts in areas affecting the disabled. Our discussion of programs which are directed toward the needs of the disabled population raises the related questions of the access of that population to the programs.

In estimating the numbers of the disabled, the surveys had to establish certain government definitions, such as the SDA's "severely disabled," "occupationally disabled," and "secondary work limitations." Similarly, the official who designs an income assistance program, or helps write a law to give preferential treatment to the disabled, must distinguish a certain group of individuals who are eligible. As we examine the array of existing programs in this section, some of the eligibility definitions and "working assumptions" on which these programs rely will emerge.

Income Restoration

The onset of disability can mean the abrupt cutting off of a person's normal wage income. Luft estimated earnings losses from long-term disability to be $22.8 billion in 1966 (13). In terms of 1971 wage levels, estimated comparable losses were $29.3 billion (14) and in terms of 1973 wages, approximately $33.2 billion. We believe these are conservative estimates.

The response to disability has been a group of public and private programs which provide substitute sources of income for the disabled, plus medical care, a wide variety of services, and, in case of death due to disability, survivor payments.

Since 1967, expenditures under these disability programs have been growing at a fast rate. Total expenditures for transfer and medical payments in the public and private sector, estimated at nearly $39 billion in 1967, had increased more than 100% to nearly $81 billion in 1973. In 1967, these aggregate expenditures were 4.9% of the Gross National Product, and by 1973 they represented 6.3%. Even after correcting for inflation, we find that total expenditures increased by 54%, or more than twice the growth in real GNP (22%) (15). If such growth trends continue, total expenditures could amount to more than $250 billion in 1990 in constant 1967 dollars (16).*

We identify more than eighty-five separate programs serving the disabled. The existence of so many programs with the same general purpose of providing benefits and services to this group raises the suspicion that fewer programs in a more natural structure might serve equally well. But before we urge alternatives to the present system, we must recognize how certain considerations of equity and efficiency affect the organization of the system. For example, it may be both equitable and efficient if two equally disabled persons are paid different benefits. It may also be equitable if two persons with identical disabilities are eligible for widely different amounts of services. Such possibilities depend upon the program in question. We must ask ourselves, "Do the programs differ in purpose, intention, and client coverage? Are there valid reasons for the differences?" One way to make some sense out of the rather bewildering array of programs which pay various cash benefits and provide medical and direct services is to classify the programs according to their rationale. For example, some benefits are paid under programs which exist only because some people decided to insure against the contingency of disability. Others exist because of a societal decision to set some level of minimal income

*These Cost Burden projections parallel the structure of the WDIS programs as outlined in Monroe Berkowitz and William G. Johnson, "Towards an Economics of Disability: The Magnitude and Structure of Transfer and Medical Costs" (17). It contrasts the $81 billion estimate including expenditures for persons below and above the labor force age, some service program expenditures not within the WDIS and some new programs such as Black Lung. On the other hand, the estimate excluded survivor payments and direct consumer medical expenditures. The differences in the composition of these estimates do not affect substantially the implications that we draw from the growth projections.

below which the needy, disabled individual should not fall. It would be most surprising if benefits and services were identical under these two types of programs. In one, the benefit levels are related directly to premiums paid, and in the other, they depend on social definitions of a particular economic condition.

We will classify the programs into five general categories based on the rationale for payments in the event of disability (Table 1). Additional categories will consist of those expenditures made directly by consumers, and those made in direct service programs.

Risk Aversion

One reason for payment under private, individual and group (including collectively-bargained) insurance plans is broadly speaking a desire on the part of the insured to avert risk.

TABLE 1

Estimated Total Disability Payments 1973

	Billions	%
Risk aversion	$29.1	35
States	8.3	10
Social Insurance	19.6	23.6
Indemnity	5.9	7.1
Income Support	18.8	22.6
Other*	1.4	1.7
	$83.1	100%

*Includes service expenditures such as for the vocational rehabilitation program which cannot be conveniently placed in any of the other categories.

Source: Evaluation of Disability Programs (15).

Individuals (groups) deem it prudent to pay some small premiums and thereby avoid the possibly large losses which they might incur should they become disabled. We group private insurances in the risk aversion category, including the disability insurance provisions of retirement plans and formal sick leave plans. In addition to these cash-transfer and paid-leave programs, hospital expense and benefits paid under medical-surgical plans are included.

The notion of private insurance being purchased in order to avert risk is a familiar one. Obviously, people differ in their attitudes towards the undertaking of risks. Those who are risk averse may choose to purchase a larger amount of insurance than those who are willing to take the chance that they may become disabled. What is perhaps more controversial is to include the group plans and the sick leave provisions, especially those that are collectively bargained fringe benefits of the job.

We believe it proper to include these plans among those which originate primarily from the desire to avert risk. Our theory is that, at a given moment of time, the individual will have a job which pays a particular salary, plus a given assortment of fringes. Given a longer time horizon, however, an individual may choose to work in a job where his compensation package is heavily weighted with fringe benefits, or he may choose a job where the principal benefits come in his pay envelope. We speculate that choices are made in accordance with the individual's or the group's propensity for, or aversion to, risk taking.

We do not include the cost of premiums as a cost of disability. The individual in paying his premiums is purchasing a service--that is, the assurance that if the contingency should arise, he will receive some compensation or services to cover his losses.

The important aspect of the "risk aversion" category is its voluntary nature. In the case of private insurance policies, it is clear that individuals purchase more or less of this commodity depending upon their income and preferences. As we look at a group of disabled and find variations in the amount of disability-related income they receive, a portion of the variance is to be explained by differences in preference for risk aversion. Admittedly, the element of choice involved in a group health plan, a sick leave or retirement plan may be difficult to discern. Yet individual discretion plays a greater role in the group collectively-bargained plan than it does in the government programs which are both universal and compulsory.

Our estimates are that in 1973 $29.1 billion were expended. This total sum includes $8.3 billion for transfers and $20.8 billion for medical costs. The $29.1 billion constituted 35% of the total $83.1 billion which we estimate as expenditures in all categories in 1973.

Status

A person who qualifies as a veteran of the armed services is eligible for certain disability transfers, medical payments, and survivor benefits. If these are service-connected benefits, they could be classified as a type

of indemnity payment or even as a kind of workers' compensation payment to compensate the veteran for the injury he incurred while in service. However, some are nonservice-connected transfers that arise primarily because of the person's status as a veteran. The same contingency befalling the nonveteran will result in a different assortment of transfers. The veteran who can demonstrate need and the existence of an impairment may qualify for a compensation payment. Under certain conditions, he is also eligible for medical services and care in a veterans hospital. The $8.3 billion in transfers, medical and direct services in 1973 for the veterans' program amounted to 10% of total expenditures for disability.

Social Insurance

Unlike the private insurance, social insurance programs are compulsory; individuals who are covered are required to contribute or to have contributions or taxes paid in their behalf. Governments may require participation in order to achieve income redistribution because of economies of scale, or to avoid dependency. Or they may require participation simply because they consider such programs meritorious.

The exact rationale for any social insurance program is a matter of controversy, and the reasons for isolating individual disability programs are not entirely clear. Aside from the worker's compensation program which will be discussed below, the social insurance programs originated in the United States with the passage of the Social Security Act in 1935. The Committee on Economic Security which formulated the original legislative proposals was anxious to construct a system which would be considered by many to be analogous to the private insurance system. They were conscious of the fact that the program required public support, and they chose a program which paid wage-related benefits financed out of payroll taxes (18). It has only been in recent years as Social Security tax rates and the wage base have increased that economists and others have begun to question the method of financing. It has been suggested that social security is more a type of tax and transfer program than an insurance program (19,20).

Discussion reached a peak in 1975 when trust fund deficits seemed imminent. Various newspaper stories about the poor financial outlook for the system prompted heated denials of shortcomings in the labor press (21) and calls for extension of programs (22). Three former HEW secretaries and all living former Social Security Commissioners joined in a statement attesting to the soundness of the Social Security system and calling attacks "a disservice to the nation" (23).

As with the old age and retirement provisions, the financing of Disability Insurance under Social Security has come in for increasingly heavy criticism (24). We shall argue that in the case of the disability programs, it is less the general financing which should cause concern than the conceptual problems associated with the definition of disability and the determination of eligibility. Such problems figure just as significantly in disability programs other than DI, but DI under Social Security is the largest governmental program and certainly the most important one dealing with long-term disability.

No comparable program for short-term disability exists in the public sector. Only five states, Puerto Rico, and the railroad industry require employers to provide temporary disability insurance. Programs vary, but in general, payments are provided for non-occupational illnesses and diseases for periods up to 26 weeks. By definition, these programs do not cover any of the long-term disabilities.

The Federal Black Lung program is a type of worker's compensation total disability payment restricted to coal workers who have been exposed to dust conditions and have symptoms of coal workers' pneumoconiosis. It is mandated by the Federal Coal Mine Health and Safety Act of 1969, as amended by the Black Lung Benefits Act of 1972 (Public Law 92-203, May 19, 1972). The program resulted in a larger than anticipated number of claims, with over 100,000 claims filed in the first month of January, 1970. Payments in 1973 totalled more than $1 billion. Originally, claims were processed by the Social Security Administration but since 1973 jurisdiction has been given to the U.S. Department of Labor. The response to this plan has had an impact on disability programs which extends beyond the narrow concern of the coal workers. The filings resulted in a greater public awareness of eligibility for Social Security Disability Insurance, and, according to the Ways and Means Committee, has contributed to an increase in claims for social security benefits (24).

It is likely that the program would not have been necessary if the individual state workers' compensation programs covered these occupational diseases. The traditional workers' compensation program had its beginning in the United States in the period prior to the first World War. It signalled a different approach to the problem of work injuries. Prior to the adoption of workers' compensation statutes in individual states, workers were entitled to redress under the common law as amended by the various employer liability statutes. Workers' compensation instituted a "liability without fault" system where payments for all work-connected injuries were to be made without assessment of negligence.

According to the findings of the National Commission on State Workmen's Compensation Laws, state legislation in this area contains many deficiencies. Payment levels have lagged behind changes in cost-of-living and wage levels, and coverage in many states is less than complete (25).

Typically, the workers' compensation programs in the states will pay benefits to persons who are temporarily disabled and to those whose injuries have left them with some permanent disability, whether of a partial or complete nature. In some states these payments are based upon the assessment of the impairment, and in others on "wage loss." In some states, various combinations and permutations of these basic factors are utilized.

Emphasis in the WDIS* is on transfer payment programs where cash payments are made. However, it is clear that the provision of services such as medical care is often a virtual substitute for cash payment. Although hospitalization plans fall into the risk aversion category, some hospital expense plans pay cash to those hospitalized. Other plans provide services--either directly or by compensating the institution. Medical care payments and services are provided

*Workers' Disability Income System

by the Medicare programs on a social insurance basis. Originally designed to cover reasonable costs of hospitalization and medical care for those over 65, Medicare was extended in 1974 to cover DI beneficiaries after 24 months of entitlement to transfer payments and to cover persons utilizing hemodialysis treatment.

All told, social insurance expenditures in 1973 were $19.6 billion or 23.6% of the total.

Income Support

In each of the social insurance programs the objective is to maintain the income of the disabled person or his family. For the most part, the benefits that are paid are related to the income the person made while he was at work, although each of the programs has a minimum benefit and a maximum benefit which tend to distort the relationship between actual wage and benefits paid. Under the public assistance programs, however, the prime rationale for payments is income support rather than income maintenance. In the field of disability, two categorical assistance programs, Aid to the Blind and Aid to the Permanently and Totally Disabled, have been replaced by the Supplemental Security Income (SSI) program.

Title III, of Public Law 92-603, the Social Security Amendments of 1972, transferred to the federal government from the states the responsibility of providing financial aid to the needy, the aged, the blind, and the disabled. The program provided for federal government benefits which could be supplemented by the states. In September, 1975, there were 1.85 million people in the disabled category and 73,875 people in the blind category receiving SSI benefits.

In addition to the SSI programs, we include a portion of the payments made under AFDC* as disability payments. Disability does play some part in causing families to fall below poverty levels. Since approximately 19% of the families receiving aid under AFDC have either incapacitated fathers or mothers in the household (26), we have taken that percent of AFDC payments and attributed it to disability. This is probably a conservative estimate as family size is significantly larger in these cases, thus requiring a larger budget. In 1973 additional AFDC payments increased disability income transfers by approximately $1.4 billion.

Income support programs, administering both transfer and medical payments, account for $18.8 billion in 1973 or 22.6% of the total expenditures.

Indemnity Payments

A large portion of the disability expenditures come not from private or social insurance programs or even from the income support programs but rather from indemnity sources. These are not programs but payments made for disability which occurs under particular circumstances. The immediate source is

*Aid to Families of Disabled Children

some liability insurance contract, but the payments are made only after harm has been shown. Liability payments where negligence can be demonstrated are the classic examples. Typically, such payments go beyond income maintenance and are based on a wider evaluation of harm which includes pain and suffering incurred by the disabled. We include automotive bodily injury, medical malpractice and miscellaneous bodily injury insurance in this category. Indemnity transfers are conservatively estimated at $5.9 billion in 1973 or 7.1% of the total.

Overlapping Categories

We believe that the classification according to rationale is a useful system. The categories, however, are not mutually exclusive. The indemnity notion lies behind liability payments made in the event of proof of negligence, but the service-connected veterans' disability payments share this notion also. Although confined to work-connected injuries, workers' compensation carries with it some element of the indemnity principle. The workers' compensation systems are different, however, in that no assessment of negligence is necessary. The payments, of course, are confined to income replacement, and do not compensate for total economic loss, or pain and suffering.

Other Programs for the Disabled

Medical care service and payment programs have obviously close relationship to cash transfers. It may be logical to go a step further and include in the expenditures of the disability system those programs which provide services other than medical care. Examples of such services are vocational rehabilitation, education, specially adapted automobiles for the disabled, the removal of architectural barriers, and the social services which are made available to public assistance recipients. For the disabled person who can benefit from them, these services may be nearly the equivalent of an increase in income.

Consideration of service programs raises the question of how to separate out expenditures for programs for the disabled from those which serve the population. Our solution is to include programs where the disabled are a target population of the program, where the disabled receive special emphasis, or where the program aims at alleviating consequences of disability. In those cases where the same program serves both the disabled and nondisabled, we have allocated expenditures in accordance with estimates of the number of disabled served (15).

The programs in the direct services category are numerous but their expenditures are relatively small in total dollar amounts ($2.3 billion or 3% of all disability expenditures in 1973). It is possible to allocate a portion of the direct service expenditures to one or the other of the five specific rationale categories. In 1973, for example, 30% of direct service expenditures ($0.7 billion) were classified in the income support category.

Some of the service programs affect veterans. These include specially adapted housing and automobiles, and educational assistance for dependents of disabled veterans. In 1973, 3% of all direct service payments ($207 million) was spent in the "status" category. Vocational rehabilitation expenditures from the social security trust fund are the only form of direct service in the "social insurance" category. They amounted to $45 million or 2% of all direct service payments in 1973.

After breaking down program expenditures into the several categories, we are left with 20 programs which all together accounted for $1.4 billion of expenditures in 1973. These programs, such as basic vocational rehabilitation, special education, vocational education, and drug and alcohol abuse programs comprise a miscellaneous category. Vocational rehabilitation programs account for over half of the expenditures in the miscellaneous group; we single it out for special attention in the next section.

In each of the direct service programs, we are able to estimate expenditures for any given year. However, several other programs and policies benefit the disabled in a general or diffuse way, and, in these cases, we have not yet been able to arrive at a valuation of benefits for a specific year. Examples include legislation which extends preference to the handicapped. The Wagner-O'Day Act requires governmental agencies to give bidding preference to workshops for the severely disabled and blind (Wagner-O'Day Act, P.L. 75-697, 52 Stat. 1196 [1938]). The 1973 Amendments to the Vocational Rehabilitation Act prohibited discrimination in hiring and mandated affirmative action programs (Rehabilitation Act of 1973, P.L. 93-112, 87 Stat. 393-394 [1973]); Sections 503 and 504). Other legislation provides direct employment opportunities by reserving for the blind the staffing of vending stands in public buildings (Randolph-Shepard Act, P.L. 74-638, 49 Stat. 1559 [1936]).

Another group of programs provides funds for research and demonstration projects in training of personnel and construction of facilities. An example would be the financing of extensive research by the Vocational Rehabilitation Administration (27). The Developmental Disability Amendments of 1970 provided funds for construction of facilities and for a survey of needs. Expenditures in this category are excluded only because of our inability to allocate benefits. It is obvious that research, training, and construction undertaken in any given year may yield a stream of benefits over a number of succeeding years.

Action has been taken to meet the needs of persons with particular types of disability. Government grants funds for the establishment of special facilities, and encourages the creation of job opportunities for such persons. It has long singled out the blind and deaf for special attention. In addition to passing the Randolph-Shepard Act, Congress chartered Gallaudet College in the District of Columbia as a liberal arts college for the deaf. The needs of other handicapped persons, however, have also been the subject of much legislation. Congress has provided for construction of research centers and training facilities for mental retardation personnel as well as for the establishment of mental health centers.

To fully understand the government's role in disability would require an examination of all health legislation, including the establishment of the research centers, the National Institutes of Health, and all special legislation for the handicapped, including those legislative provisions designed to remove discrimination against the handicapped. We would have to consider also a group of laws designed to improve the mobility of the handicapped by the removal of architectural barriers. A part of the legislation designed for the aged would also come under our purview; for example, the National Housing Acts mandate a percentage of the federal contribution to public housing for special facilities for displaced elderly and handicapped.

The system of veterans' benefits which began in this country after the Revolutionary War represents a significant portion of the government's efforts. We have already mentioned the scope of the benefits in terms of the cost of the transfers and medical payments made to veterans. The programs include educational benefits, and loan guarantees for veterans as well as the special policies which focus on payments for disability.

A major interest of government is the restoration of disabled persons to the labor market. Today each state administers a vocational rehabilitation program under a plan which conforms to federal legislation. The federal government contributes up to 80% of the funds for the rehabilitation of the handicapped, and, in addition, makes special grants for research and demonstration projects, construction of facilities, and training of personnel in this area.

The exact nature of the program varies from year to year depending upon the finances, the congressional mandates and popular will. In recent years, the programs' orientation has expanded to include the mentally ill, the mentally retarded and even the culturally disadvantaged. By 1973, the emphasis on the cuiturally disadvantaged had reached its peak and Congress voiced its renewed concern for the severely handicapped.

The rehabilitation program traditionally admits only people who have been deemed feasible for eventual placement in the labor market, whatever their specific condition or disability classification might be. As Congressional interest in the severely disabled grows, however, placement in sheltered workshops, or improved functioning in the activities of independent living have become new objectives of the program. But in the typical case, a person is admitted to the program if there is a reasonable chance that he will return to the labor market.

The program spent about $809 million in fiscal year 1974 for basic support. The average cost per rehabilitation was $2,242 for 1974 (28). In 1950, the total expenditures for the federal-state vocational rehabilitation program were only $30 million. The real boom in the expenditures began after the 1954 amendments. These enlarged the scope of the program and expanded its financing. Nevertheless, by 1965 the federal-state vocational rehabilitation program was still considerably smaller than it is today. Slightly fewer than 135,000 persons were rehabilitated and 441,000 persons served. Total expenditures of the program for that year were $154 million (29). Vocational Rehabilitation is a major program and promises to continue to grow with yearly expenditures beginning to approach $1 billion. As such, it constitutes a significant effort on the part of the government to restore disabled workers.

The Workers' Disability Income System - Summary and Conclusions

The array of transfer payment programs, together with the medical care payments, provide a surprisingly comprehensive system. Each program, however, was designed to serve a particular need and a particular population, and each is governed by a set of eligibility rules which are the product of historical circumstances and political consensus. It is not surprising to find that in spite of the vast range of programs, some disabled individuals fail to quality for any programs whereas others may be eligible for benefits from more than one source. Much depends upon the person's employment status and the circumstances under which he sustains his injury or disease.

Whatever the gaps in coverage, the system has shown an astonishing growth in expenditures. The exact increases reported vary with the measures used, the age adjustments made, and the types of programs included, but the upward trend in expenditures is apparent in all assessments.

Our examination of the WDIS reveals the close interrelationships among transfers, medical payments and direct services. A single goal, for example, the restoring of a maximum number of the disabled to an independent living status, could be accomplished by a direct service program such as vocational rehabilitation, a program providing medical care, or an increase in transfer payments. With more cash available to them, the disabled presumably could purchase restorative services from the private sector.

Total transfers increased by 96% between 1967 and 1973, and by 116% at the federal level during the same space of time. In real terms, after adjusting for inflation, transfer payments in 1973 were 47% greater than in 1967, and at the federal level, the increase was 63%.

Using a different measure of disability--transfer payments limited to ages 18 to 64--we estimate that since 1967 transfers have been increasing about 9% per year. If such trends continue, transfers will amount to nearly $115 billion in constant 1967 dollars by 1980.

Evaluation

Such increases in program costs raise inevitable questions. Are society's resources being allocated in an optimal fashion? Are the existing programs "good" or "bad?" Should they be scrapped or expanded? Is a program meeting its goals or objectives? Evaluation can help us to answer some of these questions. Ideally, we would like to have objective answers to these questions. While evaluation may not give us all the answers, it will provide us with the framework necessary to make sound decisions. We cannot assume that a program is "good" because it has worthy objectives in the eyes of some. Nor can we necessarily condemn a program which denies service to those whom we deem eligible. In order to judge a program we should know something about its efficiency, equity, effectiveness and adequacy. The purpose of this section is to provide a framework for arriving at sound decision criteria for a successful social policy.

Efficiency

We may examine efficiency from several perspectives. A universal goal is to achieve the maximum benefits that can accrue from the use of society's resources. One definition of efficiency is that an efficient allocation of resources has occurred when there is no possible reallocation of resources which can make someone better off without making another worse off.

Another perspective on efficiency arises from the explicit statement that society's resources are limited. We cannot produce everything we desire; we cannot have all the programs that we want. An efficient use of resources occurs when we produce the maximum amount of goods and services possible with a given level of resources, or when we are using the least amount of resources possible to produce a given level of goods and services. This latter perspective is the more easily applied in program evaluation. It is unequivocable that anytime we can produce the same level of goods and services at a lower cost, we will have efficiency gains by doing so.

The ease with which we can evaluate the efficiency of the various programs varies with the nature of their output. Programs which have outputs that are measurable in some physical sense are easier to evaluate in terms of efficiency than those programs which do not.

Efficiency is an objective concern. We examine the effects of the allocation of resources on the level of output. But we are also interested in who receives the output produced and consequently in the distribution of goods and services.

Equity

Questions of what is equitable are subjective. As a society we make value judgments about what ought to be, and we often formalize these value judgments into the law. For example, we have decided that those individuals who are most "severely handicapped" should have priority in the receipt of vocational rehabilitation services and we have formalized this constraint on the rehabilitation [illegible] and placed it in the statute. The rehabilitation program must now pursue efficiency goal subject to such an equity constraint.

The introduction of equity constraints may lead to a diminution of physical output. In other words, we may value the gains arising from what we perceive to be fair treatment of the handicapped as more important than any possible inefficiencies which arise from that treatment.

Reasonable people differ as to what constitutes fair treatment or how equity is defined. However, we can derive some notions about how society views equity considerations from those which are already manifest in our laws. Two notions of equity which are important are horizontal equity and vertical equity. Horizontal equity usually refers to the equal treatment of equals. For example we would like two people with the same income to pay the same level of taxes but there are grave problems in determining when two people are equals and what constitutes equal treatment. Vertical equity refers to unequal treatment of unequals.

As an example, suppose that one individual suffered a disabling injury during the year and spent three thousand dollars for medical expenditures, whereas a second person with identical income escaped this misfortune, would we want the disabled person to bear the same tax burden? Vertical equity considerations may dictate a lower tax payment for the person with the extraordinary medical expenses and our federal taxes are structured to reflect this value judgment.

Programs can be evaluated in terms of who receives their benefits and who pays for them. But there is little agreement about who should pay for programs. One point of view is that those who benefit should pay. Another, is that public programs and expenditures should lead to a more equal distribution of income. Although there is no unanimity of opinion on proportionality vis-a-vis progressivity, there is little quarrel with the proposition that regressivity is undesirable, i.e., the poor should not pay for the services of the rich. Similarly, the judicial and legislative branches of our government have formalized our wish that differences in age, race, sex, etc. be ignored in the determination of who is equal.

Effectiveness and Adequacy

We want to know how effectively a program is meeting its goals. Suppose that the only goal of the rehabilitation program were to rehabilitate 300,000 people. We could then say that the program was effective in the sense that it was meeting its goal if the record showed 300,000 rehabilitants. It should be noted that a program may be effective and inefficient, or efficient and ineffective. An efficient program is more likely to achieve its goals but may not have sufficient resources to do so.

Similarly, a program may be efficient without being adequate, and effective without being adequate. Adequacy refers to the ability of a program to meet the needs of the entire population in a problem area. Suppose we designed a program with a stated goal of training one thousand mentally retarded citizens in vocational skills. If we found that the program was training one thousand citizens a year we would say that it was an effective program. But if in fact it could be shown that a population of 20,000 mental retardates were awaiting vocational training, we would not consider it adequate to meet the demonstrated needs.

Some Evaluation Tools

Some of the standard measures of program evaluation are designed to consider the impact of the program on the distribution of income, the tax burden it generates and who bears that burden, the benefit-cost ratio of the program, and the net number of people it removes from poverty.

If we wanted to evaluate a transfer program, for example, we might begin by examining the inequalities in the distribution of income before the program and after the program. We might also calculate the number of people who were

raised above the poverty level by the receipt of program transfer payments. In addition to such distribution measures, we would attempt to insure that the transfer payment program was being administered as efficiently as possible, i.e., at the lowest possible cost.

In a service program such as the vocational rehabilitation program, we might see which income groups benefit directly from the program, and which income groups pay for the program. Dr. Donald Bellante has done so for the Florida federal-state vocational rehabilitation program. He found that the clients of the program were more frequently from the lower income groups whereas the tax burden of the program fell more heavily on higher income groups (30). In effect the program generated net transfers which were inverse to income. This would be considered by many to be a desirable property of the program.

Program Evaluation and the Consumer

Program evaluation can provide valuable information to consumers by specifying who receives what services and who pays for them. If Bellante's findings are correct we probably are more willing to support the vocational rehabilitation program because it makes positive transfers to lower income classes. Popular support for the program may lessen if it were found that the tax burden fell most heavily on the lower income classes and that the higher income classes received most of the program's expenditures.

We place different values on equivalent services received by different categories of people. It may be important for us whether a program serves the severely handicapped, the moderately handicapped, or the mildly handicapped. Program evaluation can make specific who is being served and hence form the base for recommendations for change incorporating new or different equity constraints.

The disabled consumer obviously should have an abiding interest in program evaluation. His self-interest dictates that programs be run as efficiently as possible and the more information about programs and services the disabled have, the better able they will be to use them to their full advantage.

In a free society, increased or continued expenditures on disability programs will be forthcoming only as society sees the value of those programs. Program evaluation is often a potential vehicle for making just such a demonstration. The use of benefit-cost analysis in program evaluation is a good example of this point.

Benefit-Cost Analysis and Social Investment

If society wants to allocate its resources efficiently, it is obvious there are many claims on resources and many social investments which could be made. Which of these investments to make is easy to describe theoretically, and difficult to decide objectively in the real world. If the basic goal is to maximize social well-being, we should choose those social investments which make the greatest contribution, given our resource constraints. Ideally we

would invest until that point where the incremental social benefit of the last project or social investment undertaken is equal to the incremental social cost entailed in the resource use.

Benefit-cost analysis is a technique to assist in determining which investments contribute the most to our social well-being. The method incorporates an attempt to compute all of the benefits of an investment and to compare them with all of the costs of the investment. Those projects which have ratios of benefits to cost which are greater than one are eligible candidates for funding. Those with ratios less than one would not be undertaken because they would always cost more than their value to society. In order to determine which social investments should be undertaken first, we would rank order projects by benefit-cost ratios. We would then select those with the highest ratio of benefits to costs until we exhausted our investible resources. If individual projects were perfectly divisible, we would allocate resources among the investments such that the return per unit of resource invested would be the same for all projects.

But as one can imagine, there are many problems which arise when one applies benefit-cost analysis to social investment. We examine some of these in a non-technical fashion now.

Some Problems in the Application of Benefit-Cost Analysis

One of the major difficulties is the quantification of benefits and costs. Some benefits and costs are unmeasurable by any concrete yardstick. If a severely handicapped person is provided a service that assists that person to accomplish an activity of daily living (feeding oneself), we know that the satisfaction of increased independence exists. But we do not know how to assign a value to that gain. Similarly, there are benefits and costs which are external to the program which are real but practicably unmeasurable. For instance, the fact that over 250,000 people were assisted by the federal-state vocational rehabilitation program in achieving their goal of employment generates not only direct benefits to them through their participation in the labor market, but also indirect benefits to other citizens who will share in their physical and psychic productivity. Analogous cases could be presented for costs.

Another problem in benefit-cost analysis is that the returns from social investment flow over time and since we cannot foretell the future we are uncertain about future investment yields. In addition, if benefits accrue over a period of time, we must find a technique to discount the receipt of future benefits. The value of a dollar received today, barring deflation, will be worth more than a dollar received at sometime in the future. We must select a social rate of discount which reflects society's true time preference. If we do not, we can alter the correct balance between public and private investment.

Generally, we are striving to maximize social welfare when we undertake social investment but since we cannot explicitly measure social welfare, we frequently substitute national income or gross output. This substitution can lead to distortions especially if continued growth is not synonymous with increased well-being.

Political Decision-Making and Benefit-Cost Analysis

Although there are many other factors that should be considered before using benefit-cost analysis, space limitations dictate our mentioning only one. Political constraints on what can and cannot be undertaken weigh heavily in decision-making. Benefit-cost analysis in its present state cannot quantify equity concerns and political value judgments so as to integrate them into our valuation of benefits and costs. Consequently, decisions on social investment are made in a moral, ethical, and political framework. Benefit-cost analysis is only one aid to decision-makers. It will not be the only input nor should it necessarily be.

Whether benefit-cost results are favorable or unfavorable for a specific project, society stands to profit by the information gained. If the project has a low benefit-cost ratio we may gain by transferring our resources to other uses which will more profitably serve us all. If the benefit-cost ratios for a particular project or program are high, we may use this favorable result in our quest for funds for the program. Benefit-cost ratios have been computed by many researchers for the federal-state vocational rehabilitation program. The ratios, despite different assumptions, time periods, data sets, etc., have usually been greater than one, and often significantly higher than that. We shall examine one such set of ratios as an example.

Benefit and Costs of the Federal-State Vocational Rehabilitation Program

Benefits

The chief measurable benefit of the vocational rehabilitation program is the increase in output that can be expected from the productive activity of rehabilitants. Wages, which are the usual measure of an individual's contribution to output, are compared at entry and at closure to determine if the program has increased the client's productivity.

The wage that a rehabilitation client was earning when he entered the program, if any, must be extrapolated over the client's life and discounted by the appropriate rate of interest. A similar extrapolation must be made for the wages that a client earns after completing the program. Both of these wage streams must be adjusted to reflect the probability of unemployment, injury, and mortality, and to account for the growth in the productivity of the labor force over time.

A recent study of the vocational rehabilitation program used the earnings experience of cohorts of rehabilitation clients with similar characteristics to project wages over the expected life of a client. Those clients with no wages at opening were assumed to have potential earnings, in the absence of rehabilitation, which were equal to those who were not admitted to the rehabilitation program (15).

Costs

The major costs of the vocational rehabilitation program are case service costs, which are usually variable, and overhead costs, which are primarily fixed. Typical rehabilitation costs might include those for administration, counseling, placement, medical services, diagnosis, physical and mental restoration, training, facilities usage, services provided by other agencies, etc.

One other large cost of the program is the opportunity cost of wages lost by clients while they were in the program. For instance, if a client could have earned twenty-five dollars a week but entered the rehabilitation program instead, a cost to society would be twenty-five dollars of output foregone for each week the client was in the program and unable to work.

Federal-State Vocational Rehabilitation Program as a Social Investment

Most benefit-cost ratios computed for the rehabilitation program indicate that the program is returning more to society in productivity gains than the costs expended. Some of the more conservative estimates of the ratio of benefits to costs are 5 to 1. Other estimates have run as high as 70 to 1. Our own research favors the conservative estimate.

Benefit-cost analysis is only as good as the data available and the assumptions we must make. The ratio should not be seen as a single criterion for social investment, but as a useful tool for decision-making. If we realize that the rehabilitation program returns five dollars for every one dollar we devote to it, we can state that although there may be more productive investments, the rehabilitation program is a good one.

Conclusions

Survey results do not indicate any significant increase in the numbers of the disabled. Yet, benefit programs show increases in the number of beneficiaries and payments. Such increases cannot be explained by any observable increase in the incidence of the impairments.

As the National Research Council seeks to assess the needs of the physically handicapped, it is inevitable that as needs are identified, new programs to provide for such needs will be proposed.

As one looks out at the landscape of existing programs, it is obvious that they are numerous; some must overlap, and the needs of particular persons may not be met by any existing program. It is easy to point out gaps and deficiencies but not as easy to propose economically viable solutions. Solutions to such problems must be constructed with the thorough understanding that existing programs are meant to serve different persons with differential claims on public funds. In the United States, as in every other country of the world, those persons whose impairment can be traced to war injuries or work injuries are treated differently than those whose injuries are congenital or acquired elsewhere. The person who is injured as a result of another's negligence is again treated differently than the person whose injury occurs without being able to place negligence on any individual. The veteran may have his choice among many prosthetic and orthotic devices. The person who is congenitally impaired or impaired from an accident where cause cannot be established may find himself with much less to fall back on. If he can prove he is destitute, he will become eligible for a public assistance type of program, and if he has had some work experience, he may find himself eligible for disability benefits under Social Security.

Before one rushes to the conclusion that these differences are inequitable, we must take a hard look at the alternatives. To bring everyone up to the level enjoyed by the war veteran may not be economically feasible. There may be no way to persuade the majority who are ablebodied to dispense largesse to those who are not. The whole system has not yet come to grips with the problem of legitimating the claims of the generally disabled.

In theory, the job of deciding whether or not a particular person is disabled is an impossible one. You must determine whether or not a particular individual is or is not working because of the health-related condition, always recognizing that the condition alone is almost never enough to make a person stop working. The condition operates in conjunction with other social, economic, and demographic factors.

Most workers' compensation programs are content to evaluate impairments alone. Others, as in Social Security, first decide whether or not there is a health-related condition, then make a determination as to whether that condition is sufficient when combined with other factors to justify the inability to work. The basic difficulty is that there exists a population of people who have the same condition as the disability applicant, and, who, in fact, are working. Their ability to work, despite their impairment or functional limitation, may be due to the compensating factors of age, race, sex, level of education, or possibly the opportunity structure in the market. The benefit program's experience in determining eligibility underlines the basic fact that it is not the impairment alone, but the impairment in combination with other factors that determine a person's status. I know of no way to get around such difficult interrelationships--certainly substituting the term handicapped does not alter the essential determination problem.

Rehabilitation Trends

The vocational rehabilitation program has been historically designed to orient people to the world of work (2,31), but such vocational objectives may be lost sight of with the emphasis on the "severely handicapped." The danger is that the rehabilitation program may become indistinguishable from a general medical aid or health insurance program. Then the question will arise as to why "handicapped" individuals should be singled out from others in the general population who are equally deserving and equally in need of medical care and treatment. The tie to the world of work and screening on the basis of vocational potential gives the rehabilitation program its [illegible] essential character.

Vocational rehabilitation is a program in search of a mission as it changes its targets according to various Congressional mandates. Despite such changes, it still has the problem of admitting people who are sufficiently impaired so as to require services, and yet not so impaired as to be ineligible for the labor market. I would argue that similar problems of choice, but in a more attenuated way, are to be found in developmental disability programs and educational programs for handicapped children. Their announced purpose is to serve everyone, but the realities are that choices will have to be made and priorities established in the face of de facto limited resources.

Public Policy Choices

No grand solutions can be advanced because what must come first is a clear recognition of the fact that disability is an end result which is caused by a multiplicity of factors, including physical impairment. Research on sophisticated prosthetic and orthotic appliances, on electronic devices to make the blind "see," to allow them to read print, must be encouraged. The more research and information that can be provided, within limits, the better off we all shall be.

When it comes to work potential, over and over again, it must be emphasized that labor market factors influence the extent and severity of disability. It is, after all, economic conditions and income maintenance policies, not incidence of disability, which can be altered most easily by public policy.

The idea that the problem of disability is, in part, a reflection of more basic economic trends should lead policy makers to reconsider strategies that treat impaired persons as a group of persons with an entirely unique set of problems. Emphasis on the severely disabled as clients of rehabilitation may be misplaced. If these people cannot be restored to a world of work, the alternative might well be services which are given in the general health agency, combined with some income support. It also implies a need to recognize that the prospects of rehabilitating impaired persons are seriously reduced as aggregate unemployment increases. Resources allocated for such purposes might be more usefully devoted to increasing the levels of transfer payments.

Public policies which are designed to influence the work environment probably have a higher payoff than those that are designed to train the individual. Design of jobs and the removal of barriers to mobility are useful strategies for minimization of disability. At the same time, increased emphasis is needed on the development of incentives that would lead employers to use techniques of job adjustments that are now available. Reallocation of resources towards job subsidy and job redesign may be more useful than spending on activities that concentrate solely on the retraining of the individual.

We are rapidly moving into a world where the impaired are demanding their "rights," even though these are not explicitly delineated. The passage of anti-discrimination and affirmative action laws is an indication of such a trend, and there is increasing talk about access to rehabilitation services becoming a matter of right. Affirmative action programs and anti-discrimination programs are directly oriented to changing the environment in which the impaired seek jobs. It will be years before we iron out all the difficulties and devise rules and regulations and appropriate definitions. The laws are meant to include those who are substantially limited; at the same time, they are confined to those likely to experience difficulty in securing, retaining or advancing in employment. Although the difficulties of enforcement can be great, the programs are aimed in the appropriate direction of eliminating unjustifiable barriers to work.

The multiple causality underlying disability yields another conclusion. It is impossible to disentangle on an individual basis the exact contribution of demographic factors, economic conditions, and physical impairment to the person's disability. In such a situation, it might be wise to let the individual himself judge how his situation can best be remedied. Rather than devise yet another program or combine existing programs, it might be wise public policy to provide general resources to people who find themselves out of the labor market.

Such resources could be used by the persons in accordance with their own preference structure. Experimentation in the area of allowing the impaired the exercise of free choice in choosing services is needed. Private agencies provide most of the rehabilitation services, and it may be easier to define services eligible for such voucher payments than to determine who shall be eligible for existing programs. At least we might conclude that the problems are of comparable difficulty. Rather than devise another set of procrustean programs, we might at least experiment with allowing the impaired to choose their own paths to avoid, eliminate or minimize disability.

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SOCIAL ISSUES IN REHABILITATION

by

Robert Morris, D.S.W.*

Kirstein Professor of Social Planning
Director, Levinson Policy Institute

The Florence Heller Graduate School
for Advanced Studies in Social Welfare
Brandeis University
Waltham, Massachusetts

*The interpretations and conclusions expressed in this paper are the author's and are not intended to represent the position or policy of any institution or agency.

Discussion of the social issue in rehabilitation must be presented in the context of the systemic relationships which link rehabilitation on the one hand to medical efforts to either prevent or treat physical handicap in the curative sense, and, at the other extreme, to the life adjustment which follows the completion of rehabilitation. Scientific preconceptions and legislative policy constraints have often limited attention to the hope for preventing disability, to treating it in the curative sense, or, failing success, to restoration of function through rehabilitation. The achievements in cure and in rehabilitation to date flow from the premise that the severity of disability can be reduced by technical and professional means. Restoration of full or partial functioning, measured by either economic or physical independence, has relied on a relatively short time framework within which to succeed, ignoring consequences when there is an irreversible residual severe disability or handicap. Rehabilitation programs generally address such consequences either by a primarily psychological approach to assist individuals to accept emotionally and psychologically the realities of their physical condition; or family members are treated as residual "social services" to which patients can be discharged when rehabilitation technology has reached its maximum effect.

The following discussion concentrates on the most clear-cut arena for examining social implications, that involving the severely disabled or handicapped who, because of that disability, will require the attention sometime during the day or the week of another adult, and whose disability is not amenable to further restorative or curative intervention.

Absence of Comprehensive Aggregate Data - Increases in Prevalence of Disability

Certain evidence is noted below which requires a reconsideration of present assumptions which undergird present rehabilitation programs. Current policies, programs, and financing assume that disability can best be contained or dealt with through a primary emphasis upon cure of condition or restoration of function. Although great achievements have been made operating on this assumption, it now appears that success in treatment and rehabilitation produces an unexpected consequence - a substantial <u>increase</u> in the prevalence of disability and, possibly, even in the incidence of disability. In oversimplified terms, it can be argued that success in keeping persons alive with disabling conditions increases the total, and perhaps proportionate number of persons who continue to require the attention of others after the completion of both treatment and rehabilitation. It is the provision of this subsequent care for living which constitutes a major policy dilemma.

Some of the evidence pointing to the increasing prevalence of disability is summarized here. While some of this evidence may be explained by the discovery of previously hidden conditions by better case finding or through relaxation of eligibility and improvement of benefit standards in public programs, the cumulative evidence suggests strongly that a much more serious trend is underway. The initiation of this trend was identified at least as early as World War II, when Moser's volume <u>Diseases of Medical Progress</u> (1)

identified new medical and rehabilitative conditions emerging as a result of new treatment forms not previously known, implying the need for a textbook on "Diseases of Medical Progress."

If we take a generic approach to disability, one which regards the common aspects of disability and which aggregates all forms of severe disability regardless of age or of etiology, then it appears that long-term irreversible disability is a significantly growing phenomenon, growing both in incidence and in prevalence.

A recent report of the Social Security Administration (2) indicates that between 1960 and 1970 there was an increase of 225 percent in the number of Social Security beneficiaries, between the ages of 18 and 64, who suffer from severe, permanent, disabling disabilities which prevented the performance of normal major tasks. In this same period, among the total worker beneficiary population, the proportion of the totally disabled increased from 5.3 to 10.1 percent, nearly double.

A recent attempt (3) to assess the cost of disability finds that nearly $83 billion of health, medical and transfer expenditures are in some way implicated in serving the disabled medically. This includes, of course, episodic and acute treatment of health conditions which are diagnostically identified as chronic illnesses plus disability-triggered income transfers.

These sums are distributed as follows: medical - $46.5 billion; income transfers - $34 billion; direct services - $2.3 billion.

Such evidence is, of course, not conclusive and can be explained by a variety of factors: better case finding, liberalization of benefits, more generous administrative or clinical procedures. However, a closer examination of several more specific items suggests that an optimistic view is premature at best, and possibly unwarranted.

1. In 1937, the Children's Bureau reported that there were twenty-four severely crippled children per 10,000 population who were beneficiaries of that program. In 1957, the same program reported forty-seven crippled children per 10,000 population with like conditions.

2. In 1960, the Social Security Administration made annual lifetime payments to 100,000 permanently disabled children of Social Security beneficiaries - those permanently disabled before the age of 18 which rendered them incapable of economic employment after that age. In 1972, this number - an accumulative one - had increased to 300,000.

3. There is increasing evidence of a perceptible increase in the number and proportion of infants who are born with severe malformations or with early life-endangering conditions. For example, our success in keeping alive children born with very low birth weight or with severe respiratory distress symptoms has been accompanied by evidence that a significant proportion of such children are likely to survive with permanent central nervous system defects (6 percent of those with low birth weights and 19 percent of those

with severe respiratory symptoms). While much has been made of the very great success in conquering the disabilities of poliomyelitis, there has been no comparative study which seeks to balance such dramatic gains with the kind of equally dramatic "losses" which would permit us to assess whether, overall, there is increase or decrease in disability.

4. Finally, since 1900, the decline in infant mortality, and improvements in nutrition and economic well-being have greatly enlarged the proportion of older persons who now survive into their 70th and 80th years. By current projections, while the total population is expected to grow by only 10 percent in the next ten years, the population over 75 years of age is expected to grow by 22 percent. It is this over 75 population which contains a very large reservoir of permanent disablement, long-term chronic disability, and represents the largest consumption of hospital or long-term care resources.

Since 1940, we have found ways to keep young adults who break their spinal cords in accidents alive for decades although they are permanently paralyzed from neck or waist down. In 1939, such patients usually died within a year or two (4).

5. In the aggregate, between 6 and 25 million persons not in institutions may be in the scope of our discussion. The Committee planning the 1976 White House Conference on Disability estimates 35 million American citizens to be disabled. This is undoubtedly a journalistic exaggeration which includes relatively minor vision and hearing handicaps. But even a more conservative estimate, limited to persons who are unable to perform their major normal functions in life, finds an estimated 6 million persons of all ages not in institutions, but who need another person's regular attention over time (5). This need does not negate the need to normalize their social acceptance as to work, education, love, etc.

The problem of developing community services must be attacked with the recognition that there has probably been a radical shift in the nature of our health problem: a shift accounted for by (1) technical capacity to keep alive fragile infants; (2) to keep the young, severely injured alive for decades (spinal cord injured); (3) to keep older adults alive for years with severe disability (6).

Recent studies in spina bifida, in chronic brain syndrome, in central nervous system defect in newborn infants enlarge these data; all point to additional and previously unrecognized conditions in which survival rates, increase in life expectancy, and persistence of severe disability can all be associated.

The implications of these tendencies have thus far been obscured by fragmentary or narrowly categorized approaches to the phenomenon. Conditions and developments are treated according to etiology, to diagnostic category, or to age. While the numbers and proportions of persons involved in any one disease entity or age category may seem to be relatively small, this segmentation encourages the belief that somehow the undesirable tendencies are offset by substantial gains elsewhere in the health and rehabilitation spectrum.

Except for the kinds of information alluded to in this manuscript, there is no comprehensive attempt to assess--over time--the aggregated trend line in severe disability not amenable for restoration. Such attempts at comprehensiveness as have been made by the National Center for Health Statistics are diminished by reliance upon self-report or by a reliance on so general a definition of disability as to mix together those persons with handicaps which are not severely disabling and those which are severely disabling. The effect of including in the total individuals with minor visual, hearing, and other losses which are remediable by present prostheses, tends to distract attention from the underlying problems by a trivializing of the seriousness of the large totals of disability which are thus produced.

Neglect of Post-Rehabilitation Situations in Severe Disability

Aside from improved information about severe disability and its trend in the United States, despite the large investments in cure and in restoration, the question must still be asked whether anything more is needed than increased effort in restoration. If the trends of the past forty or fifty years are taken as meaningful--that the prevalence and perhaps the incidence of severe disability has increased despite the dramatic advances in medical care and rehabilitation--then it can reasonably be argued that there is no development on the scientific horizon which promises a trend reversal through any major breakthrough in our capacity to restore to full independent functioning those individuals whose life expectancy is so dramatically extended.

Proceeding on this assumption, one must then question a second assumption, namely, that once medicine and rehabilitation have completed their maximum benefits the individual patient is either capable of functioning as a free-standing and wholly independent person or can be safely returned to his family which then undertakes the responsibility for whatever continuing non-rehabilitation care is required.

Changing Family Capacities

There has not been adequate analysis of the interface between family capacity, independent functioning and social provision--at least in the case of severe disability. Current assumptions about family capacity to assume residual responsibility needs to be reexamined and probably challenged. This challenge comes not so much because of any conviction that the family is less willing to bear traditional burdens. Rather, there have occurred basic changes in the demography of the United States which have seriously undermined the capacity of the family, as a social institution, to perform some functions hitherto expected of it. For example, decline in family size has undoubtedly produced a significant thinning-out in the extensiveness and density of family networks, meaning the network of cousins, aunts, uncles, etc., who can be turned to for help in crisis. Further, the national economy has drawn so large a proportion of all adults into the labor force--including not only male breadwinners, but between 40-50 percent of women, mothers, and wives, and teen-agers--that this attenuated family network is further limited in its

present capacity to perform stay-at-home functions for disabled family members. To this must be added the significant finding from various studies that a large proportion (in some studies as much as 1/3 to 1/2) of all severely disabled older persons lack family ties altogether.

Although these data require further strengthening and analysis, they are sufficiently powerful in their present form to force attention to the changing boundary between family responsibility and social provision. Some small-scale studies (7) indicate that severely disabled persons discharged from hospitals will, at the first dischage, have willing and helpful family members assume responsibility in 70 percent of the cases; but with prolonged disability, successive hospitalizations, and lacking social supports from health or welfare agencies in the post-hospital period, the proportion of cases with capable family members dropped to 30 percent.

Distorting Effects of Severe Disability on Health and Welfare Systems

The lack of attention to the continuing personal and physical care needs of the severely disabled, whose rehabilitation does not restore them to completely independent functioning, also produces severe distortions in other basic social organizations, mainly health and welfare systems. Severe distortions are seen in such evidence as the following:

1. The large proportion of patients in nursing homes and other long-term institutions who are in them for social, rather than medical reasons--the percentages ranging from 15-50 percent.

2. The proportion of acute general hospital beds and days care devoted to the chronically ill, some proportion of which utilization is accounted for by delays in discharge and in repeated hospital readmissions--often due to lack of appropriate home care arrangements. The Nursing Home Telemedicine experimental program at Boston City Hospital, for example, was able to reduce the number of hospital admissions by 10 percent and the number of hospital days care by 35 percent for a study group of the chronically ill for whom acceptable alternative institutional arrangements were made in the post-hospital period; similar results have been produced in small pilot programs to keep patients in their own homes.

3. There has been a distortion in public expenditure. Some proportion (the amount unknown) of increases in Medicaid and Medicare expenditures are clearly traceable to expenditure for care in nursing homes at a high level of cost, when a lower level of expenditure for institutional alternatives might be acceptable, and by increase in high hospital costs which might be reduced by more expeditious discharge or reduction in readmission if suitable alternatives were available either at home or in lower cost institutions.

4. Finally, distortions result when long-term care institutions and, especially, proprietary nursing homes in a commendable desire to improve quality of care are pressed by legislation and publicity to increase medical and therapeutic or rehabilitative services at a relatively high cost for patients for whom such treatment is frequently not relevant and who might benefit from less costly services.

In addition to such distortions in service systems and public expenditures, the distress imposed upon families has not really been probed when families are forced to receive severely disabled family members from rehabilitation and medical services without either adequate counseling to accept the responsibility or supplemental supportive services to assist them in carrying new burdens. The Brandeis University study mentioned above (6) found that in 60-70 percent of the cases discharged from long-term hospitals to family care, family members assumed full care responsibility for severely disabled persons without receiving any supplementary help from any organized agency. It is admittedly difficult to separate public responsibility from that of the family, but evidence is clear that, not only is there family suffering, but a significant proportion of willing and able family members break down in the process of caring alone and discontinue their care altogether. Full-time family care is replaced by full-time public care paid for by tax sources such as Medicaid. The opportunity to retain partial family care, supplemented by partial public support services, is lost by the present all-or-nothing approach. In the cases of families with very small children, born with severe birth defects which are not remediable, we do not even have comprehensive information about how families do, in fact, cope; and only recently have studies been initiated to ascertain how families do manage in the first three years of the life of a severely disabled child.

In light of the foregoing, any attention to the social sequelae of severe, irreversible disability requires attention to at least the following issues--attention which has not yet been systematically provided:

Organized arrangements for personal care services to supplement or complement personal and family capacities: such services are not simply a function of income replacement. Income replacement, aside from the fact that it is always below the level of normal earnings, is calculated on the requirements of an able-bodied person in an able-bodied family. The severely disabled person has additional requirements which are not included in income replacement standards. These plus, or above normal needs, involve primarily the costs of attention of other adults to provide the minimum mobility services inside or outside of the household, food preparation, household cleaning, chore services, possibly bathing and personal cleanliness, shopping, and the like.

Such supplementary services do not need to be full or part-time, but need to be regularly available. They can be provided by substitute group homes which are less than institutional in character, such as those used by the Veterans Administration, or by day care centers with physical/personal care capacity. Least developed are care-in-the-home services available for long periods of time. Such labor intensive care services are cost-justified by use of less skilled manpower. If properly organized, they might incidentally contribute to a reduction in unemployment.

Present home health agencies constitute an in-place service network upon which to build. Existing home health services are precluded, by public financing policy, from providing low skill personal care services for very long periods of time.

Such personal care services are required in three different types of situations: (a) where families are willing and able to care but where the risk of family breakdown in capacity is identifiable; (b) where family members are present but reluctant, which reluctance might be overcome with supplemental incentives to move them into a more "willing family" status; (c) the disabled without family members but not so disabled as to require twenty-four hour attention.

Attention to financing arrangements is also required for the provision of the foregoing personal care services to complement treatment and rehabilitation. Financing involves attention not yet adequately given to the proper borderline between family obligations and public provision. Disability payments to cover personal care costs can be made on a cash basis as in some European countries, or via a direct public service provision. Needed are analyses of such alternatives.

There exists the possibility that such needs could be met by insurance means, much as active medical treatment is now financed, but this prospect has hardly been investigated.

Financing considerations also require attention to the appropriate administrative and organizational medium through which such services are to be handled. Shall financing and administration be handled within the rehabilitation system, as an extension of the health system, or as a part of the welfare system? Each model has drawbacks--medicine and rehabilitation have little tradition or background in lifetime care, whereas welfare is limited by its public image and by its preoccupation with financial provision for the economically unstable poor whose numbers overwhelm that of the disabled.

Assessment techniques and organization require much more study than has yet been given. Assessment of personal care needs is not suitably distinguished from rehabilitation potential assessment. It is not at all clear whether both levels of assessment can be provided by active clinical centers such as hospitals and rehabilitation centers, by specialized assessment teams for the chronically ill based on active treatment centers, or whether wholly independent centers are required when lifetime care as distinguished from treatment is required.

Related to such issues is the question of administration. There is no good evidence available by which to choose between comprehensive personal care agencies which deliver the full range of alternative services and comprehensive financing (as through insurance) which pays a multitude of single person service agencies--one for chore service, one for mobility, one for feeding, one for homemakers, etc.

There are, in addition, other psychological and social services required to assist families and patients to tolerate and to live with disability. In the best institutions, such psychological help is now provided on a short-term basis for a patient and family members. What may be required is a longer-term provision of psycho-social services in order to continuously reinforce family and patient morale.

Other Social Dimensions

Other questions that require attention include: the potential of specially designed, segregated housing or modification in the routine construction of normal housing to accommodate the disabled; the provision of educational opportunities for the severely disabled child, young adult and adult--especially the introduction of the disabled into the mainstream of educational opportunities; and the organizational devices to smooth the interface between medical rehabilitation, welfare, and personal care supportive systems.

These additional dimensions are scientifically demanding because they require close attention to the interplay between major aspects of modern life, but cannot be dealt with by loose, ambiguous appeals to comprehensive or holistic idealization. While all acts may somehow be associated with all others, there are specific inter-system relationships which need to be examined. Unfortunately, present organization in this field is still dominated by segmental, specialist investigation.

Two examples illustrate what needs doing. The first of these has to do with professional practices. The active phase of rehabilitation is best begun early; but, except for a few research centers, the medical treatment of disability threatening illness or trauma is carried on independently of rehabilitation programs. The latter are engaged at the end of the medical treatment process (seen as cure) and often by referral after discharge. Except for lip service appeals for early collaboration, there are few tested standards about such questions as these: When should rehabilitation personnel be first involved? How is rehabilitation best initiated, practically, when most hospitals and physicians and group practices lack rehabilitation capacity? Should the team concept be broadened out, or does it have efficiency/effective limitations?

In like manner, what should be the relationship between general hospitals, insurance companies, and long-term care or rehabilitation organizations, qua organization. Are referral procedures sufficient or is a more structured contractual arrangement desirable? In a few test centers, hospital personnel assume professional responsibility for after care, as in nursing homes and in-home care. Is this productive or does it increase a bureaucratic overload?

The second illustration touches on psycho-social interrelationships. How can institutions better respond to individual patient needs? To answer such a question, more needs to be known about the conditions which rupture or disrupt family network capacity to cope; about the alternative ways in which medical/rehabilitation/social help can reinforce national family systems

rather than displacing them. The social and behavioral sciences have studied these issues but such science is not often integrated into rehabilitation research and operation.

In a real sense, persons needing rehabilitation also have needs which involve all of modern society: medicine, employment and occupation, education, housing, transportation, and leisure provision. But the handicapped population is still relatively small and the challenge is how to distribute and balance majority and minority wants within a limited resource framework. While there are few answers now available for these larger issues, attention can be paid to the building up of empirical evidence from research and experience so that answers become more clear over time. Rehabilitation as a technical process grew by such means. The social issues which follow such technical success require a similar evolution.

Social Aspects of Short-Term Rehabilitation

Some of the matters touched upon thus far are also relevant to shorter term aspects of rehabilitation, but since these have been dealt with elsewhere, the social dimension of restoration of function requires less attention here.

Professional practice and organizational linkages are as relevant in short-term restoration as for long-term irreversible disability. It is less clear just how the restored person fares in subsequent years. Does cure or restoration work more or less permanently? Or are there later lapses which are not now traced out but which, if understood, could produce better means to prevent future relapse?

The family in rehabilitation also needs further attention, especially as regards the present bias in favor of vocational as against self-care rehabilitation. With diminishing family networks and the manpower demands for all able-bodied adults, including women, is functional self-care as much an aim of rehabilitation as is vocational retraining, viewed as part of national manpower policies? Would more stress on functional self-care, even with short-term rehabilitation, produce wider labor force participation, or is there a final limit to the capacity to shape independently functioning persons?

Suggested Steps

The following specific steps would be valuable if the social dimension of rehabilitation is to have adequate attention and if the distortions previously alluded to are to be avoided:

1. An improvement in present data base governing severe disability, especially separation of the severely disabled requiring continuing attention from others and a reaggregation of such data on a generic basis ignoring age and cause of disability;

2. The development of appropriate public policies for the post-curative lifetime care which this population requires;

3. An examination of alternate means to implement policies: what population to begin with, what administrative location is best for development, and what alternative models are available--bearing in mind, costs, administrative simplicity, and the effects on patients' lives;

4. Testing of models and their evaluation.

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PUBLIC EXPECTATIONS

by

Albert T. Pimentel*

Assistant to
the President for Public Service
Gallaudet College
Washington, D.C.

*The interpretations and conclusions expressed in this paper are the author's and are not intended to represent the position or policy of any institution or agency.

INTRODUCTION

Today legislative authority and public programs are expanding to mount a major attack on the needs of citizens with disabilities. Presumably, this commitment by the federal government reflects the support of the population. A review of the Congressional committee hearings and the diverse input from state agencies, private organizations and individual citizens tends to support the supposition that the Congress does not operate in a vacuum where the needs of disabled American children and adults have been concerned. This paper, then, will examine where we are publicly in programs for the handicapped, and will describe the historic process in legislation that brought us to our current status.

In education we currently have P.L. 94-142, the Education for All Handicapped Children Act of 1975. This Act, still in the process of being developed, states that all handicapped children shall be included in the education process. It places the responsibility for carrying out this mandate on the local education agencies. A vastly increased amount of public funds is authorized in the law and will be allocated to the states to support this huge undertaking.

P.L. 94-142 goes considerably beyond previous legislation. It not only increases the involvement of the federal government financially in public education for handicapped children, but it also prescribes the manner in which programs will be administered, and children will be evaluated. It further mandates an individually written education plan for each child.

This law evolved from what was recognized as the exclusion of many handicapped children from the education process. P.L. 94-142 aims to take handicapped children out of custodial institution settings, placing responsibility for their education with local public schools. Another emphasis is on the inclusion of handicapped children directly in regular classrooms with non-handicapped children. The presumption is that this close association will both improve the quality of education of handicapped children and lessen negative attitudes among other children and adults through social interaction.

The federal/state vocational rehabilitation program today functions under the provisions of the 1973 Vocational Rehabilitation Act. This Act broke considerable new ground. It mandates that severely handicapped citizens shall receive priority in services. The Act also authorized the establishment of an Office for Handicapped Individuals, an Architectural and Transportation Barriers Compliance Board, and, as the Act was amended in 1974, expansion of the Office for the Blind and Visually Impaired and service to blind citizens. The 1974 Amendments further authorized a major national White House Conference for Handicapped Individuals. Also authorized in 1973 were new thrusts in civil rights for the handicapped and a program of affirmative action involving handicapped employees on the part of contractors who do business with the federal government.

Most importantly the current vocational rehabilitation program mandates direct involvement of handicapped persons in all procedures. We see mandated in these various new authorizations requirements that handicapped people be hired, appointed to councils and otherwise given the major role in carrying out the programs. Further, in actual provision of vocational rehabilitation services an individually written rehabilitation program must be developed for each client, with the client directly participating in the process of developing the plan. The emphasis in the law carries this out by placing responsibility directly in the hands of handicapped citizens themselves.

With the above description of current public expectations it is appropriate to review the history of this evolution. What follows is a summary of legislative history, including only those laws that basically expanded public programs.

LEGISLATIVE HISTORY

Vocational Rehabilitation

1918 P.L. 65-178, the Soldier Rehabilitation Act put the government in the rehabilitation business. The Federal Board of Vocational Education, created the previous year, was authorized to provide vocational rehabilitation programs to disabled veterans. This program was formally terminated in 1928.

1920 P.L. 66-236, the Civilian Vocational Rehabilitation Act. It is one of the oldest grant-in-aid programs for providing services for individuals. Services were limited to counseling, job training, artificial limbs and other prosthetic devices, and job placement.

1935 The Social Security Act included permanent authorization for the Civilian Vocational Rehabilitation Act, which had been renewed a number of times without essential change in service authorization.

1943 P.L. 78-113, the Vocational Rehabilitation Act Amendments. This legislation was important. Disabled workers had demonstrated their excellent work potential during the war years, replacing workers who left the civilian work force for military service. The 1943 Act broadened the concept of vocational rehabilitation, including mentally handicapped and the mentally ill in the program. This Act also corrected what had previously been very varied levels of commitments by states. This Act put the program on a national basis, and provided more uniformity of program activity in the states. Added service authority included coverage for specified corrective surgery or therapeutic treatment necessary to reduce or eliminate a disability. Administration of the program was transferred from the Commission of Education to the Federal Security Agency. Problems not addressed included the still limited financial resources for the approximately 50,000 persons being rehabilitated. No provision was made for research and professional training.

1954 P.L. 83-565. Rehabilitation Act Amendments. This was a year of sweeping improvements. For the first time, provisions for research, demonstration and training activities were included. A formula basis was developed with an increased federal share of funds going to states with large populations and relatively low per capita income. Also developed was a new system of project grants for improvement and extension of services. Authorizations included the use of Federal funds to expand, modernize and equip rehabilitation facilities and workshops. Through the Hill-Burton Act, funds became available for the continuation of rehabilitation facilities. Between 1960 and 1965, annual rehabilitation increased from 88,000 to 135,000 persons.

1965 P.L. 89-333, Rehabilitation Act Amendments. The primary focus of this legislation was on developing a closer working alliance of the public and voluntary agencies. The rehabilitation program was significantly expanded again and with a substantial increase in its financial base. Particularly, services to the severely disabled, the mentally retarded, and the deaf were increased. A commission on architectural barriers was established. Emphasis was placed on encouraging more and better workshops and vocationally oriented rehabilitation facilities. Grants specifically for comprehensive state-wide planning were authorized.

Education of the Handicapped

Education provisions for handicapped children has had a different history from that of the vocational rehabilitation movement. A history of the most significant steps taken in the public domain follows:

1864 President Lincoln signed a bill into law establishing a national college for the deaf later to be known as Gallaudet College.

1879 Congress enacted legislation providing financial support to the American Printing House for the Blind.

No other federal legislation on behalf of handicapped children emerged for three quarters of a century. Generally, the deep roots of public education as a local and state responsibility were likely the basis for this hiatus.

1954 P.L. 83-531, the Cooperative Research Act. This law provided research grants for education, including in 1957, funds earmarked specifically for the education of mentally retarded children.

1958 P.L. 85-905, the Captioned Films for the Deaf Program. This program originally focused on cultural enrichment and recreation, was amended in 1962, and in 1967 extended the program to include all handicapped children requiring special education. The program includes major components in educational media and involves research and training activities.

1958 P.L. 85-926 authorized grants to educational institutions to prepare professional personnel to train teachers of mentally retarded children. In 1961 the Congress enacted legislation, P.L. 87-276, authorizing support for training classroom teachers of the deaf. In 1963, this concept was greatly expanded to include federal support for the training of teachers for children who are hard-of-hearing, speech impaired, visually impaired, seriously emotionally disturbed, crippled or have other health impairments. Importantly, this same expansion of authority, P.L. 88-164, for the first time authorized grants for research and demonstration projects in the education of handicapped children. A 1965 amendment to this law further authorized construction, equipping and operation of facilities for research and related purposes.

1965 This was a year of major federal legislative commitments to handicapped children. P.L. 89-10, the Elementary and Secondary Education Act and its later amendments, provided directly for important assistance to handicapped children through local education agencies. An amendment to this Act P.L. 89-313, brought assistance through state agencies to state-supported schools for the deaf, retarded, etc., not eligible under the original law.

1965 P.L. 89-36, the National Technical Institute for the Deaf Act. This legislation authorized the establishment and operation of a post-secondary technical training facility for young adults who are deaf. This facility now exists as part of the Rochester Institute of Technology in Rochester, New York and complements Gallaudet College, which provides a liberal arts education for deaf people.

1966 Further legislation in behalf of deaf children was the Model Secondary School for the Deaf Act to be established and operated by Gallaudet College.

1966 Perhaps a culmination of all of this activity contained in the 1966 amendments to the Elementary and Secondary Education Act was the establishment of a National Advisory Committee on Handicapped Children to make recommendations concerning programs carried on for handicapped children by the Office of Education. Additionally, the Congress established the Bureau of Education for the Handicapped to centralize and administer various federal programs previously enacted.

1967 Regional resource centers to determine special education needs for handicapped children and to help local agencies to develop programs to meet identified needs, and the establishment of regional centers for deaf-blind children were part of the new Elementary and Secondary Education Act amendments.

1968 P.L. 90-538, Handicapped Children's Early Assistance Act authorized establishment of experimental pre-school and early education programs for handicapped children.

1968 P.L. 90-576, Vocational Education Act Amendments. This Act, as amended, earmarked ten percent of vocational education funds allocated to the states for use solely for vocational education activities in behalf of handicapped people. Resulting was rapid development, particularly among junior college and community college programs, of specialized vocation education offices and services for students with physical disabilities who wished to receive additional training. These programs remain in place and continue to provide important services.

1972 P.L. 93-380, Education of the Handicapped Act. This Act assured funds for the education of handicapped children to state education agencies based on a population formula involving children from the age of three to twenty-one. This Act formed the base for the current much expanded law of P.L. 94-142, the current law.

Other Federal Commitments

Space does not permit fuller description of other vital federal commitments to disabled citizens. Perhaps the largest program in terms of numbers served and dollars allocated is the program for disabled veterans. This program continues to operate separately from the vocational rehabilitation program. Several programs exist within the Department of Labor. The Manpower Administration and the Employment Standards Administration of the Department of Labor possess authority and programs specifically applicable to handicapped citizens. No previous mention has been made of the large Library of Congress and its Division for the Blind and Physically Handicapped. This program, initially limited to blind persons, now constitutes an important resource in terms of numbers of persons served and funds allocated for the program. New federal programs such as the Developmental Disabilities Act and the Head Start Program provide potential for research activities as well as direct services to handicapped children through state agencies.

The Partnership for Health Amendments of 1967 (P.L. 90-174) should be of particular interest to the scientific community. Its research in health services are applicable to the handicapped. A description of this provision reads as follows: "To enlist the Nation's best minds and most vigorous institutions in a research and development program that encompasses every element of the health services system, a National Center for Health Services Research will be established within the Department of Health, Education, and Welfare."

Perhaps of greatest importance in looking at federal activities is the constantly articulated statement that all programs, regardless of the absence of special language identifying handicapped children and adults, are available for use in behalf of handicapped citizens. Utilization of this broader authority is dependent on the determination of constituents. There have been numerous instances where the broad resources of federal programs have been "tapped" and benefitted handicapped citizens; while these programs were not developed with disabled citizens in mind, services to them were entirely in accord with the provisions of the programs in question.

ROLE OF CONSUMERS

It is appropriate to conclude this overview of public expectations with some emphasis on the role of consumers in shaping public opinion and in obtaining needed legislation. For many years national organizations of the handicapped have existed. A number of consumer organizations are well over fifty years old. In the last ten to fifteen years these organizations have become increasingly vocal in presenting their concerns to the general public. It has become routine for consumer organizations to testify before Congressional hearings on pending legislation, or on oversight committee hearings on the administration of public programs. This new participation of handicapped citizens in shaping their own destinies appears to have accomplished more legislation than the former practice of hearing mostly from professional organizations who presented and attempted to represent the needs of handicapped people. Legislators and program administrators who are accustomed to listening to many concerns and requests in the course of their work have frequently remarked that a better and clearer case of need becomes evident when handicapped Americans speak for themselves. In a sense, the current status is a tribute not only to the American way of life, but to some extent to the fact that a good number of handicapped Americans have already benefitted substantially from the system to the point where they are able to articulate well the program needs for future generations. Lest this appear that all is well and satisfactory, all that has been presented is intended to serve as a new base for bringing forth heretofore unused resources. Particularly the scientific community should be able to improve directly the still cumbersome means that handicapped people use in attempting to relieve some of the handicapping effects of their disabilities.

SUMMARY OF PUBLIC EXPECTATIONS

1. Families with handicapped children expect their children to be included in free public education programs appropriate to individual needs.

2. Young handicapped adults expect to participate in a wide variety of post-secondary programs.

3. Vocational rehabilitation counselors are expected to be sensitive and responsive to the training and career objectives of their clients.

4. Disabled veterans expect the nation to demonstrate a special responsibility to individuals with service-connected disabilities.

5. Consumer organizations expect to be involved in Congressional deliberations whenever matters affecting the handicapped are being considered. They expect the same degree of participation at state and local government levels.

6. Handicapped Americans expect to be included on advisory committees and otherwise consulted whenever governmental contracts and grants involving research and training, or service delivery activities for the handicapped are made to private agencies and organizations.

7. Through various current national programs it is expected that:

   a) Employment opportunities for the handicapped will increase especially as a result of mandatory affirmative action provisions for federal contractors.

   b) Architectural and transportation barriers will decrease as a result of such improvements as permanent staff on the Architectural and Transportation Compliance Board.

   c) Basic research will be given a higher priority, with the scientific community contributing some of its talent and resources to long unresolved physical and environmental problems.

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CONSUMER PERSPECTIVES

by

Albert T. Pimentel*

Assistant to the President for Public Service
Gallaudet College
Washington, D.C.

*The interpretations and conclusions expressed in this paper are the author's and are not intended to represent the position or policy of any institution or agency.

The contributions made by science and technology in the 1960's and the 1970's are marvelous. Without doubt, placing a man on the moon and landing a rocket on Mars are stellar achievements. Handicapped American citizens are left to witness these "miracles," while seeing almost no technological advancement in the areas affecting their own disabilities. Considering such problems as the attitudes of the general public towards the handicapped, architectural barriers in the environment, or specific technical needs for those suffering various disabilities, a rather dismal record emerges when compared with improvements in life enjoyed by the general public.

To put this situation in perspective, it is relevant to point to what has been accomplished. Infantile paralysis or poliomyelitis can now be prevented. Numerous individuals who would have been polio victims are physically whole persons. Epilepsy, which is still with us and is still a problem, is better controlled medically. Negative public attitudes, while remaining a problem, particularly in the employment area, have improved somewhat. Some research has been done to assist blind persons in reading and in mobility. Blind people, however, are still waiting for the day of routine, practical application of laboratory advances in these and other areas. Hearing impaired individuals with certain types of middle ear problems have seen surgical restoration of most of their hearing. Advances in medicine have benefited mentally ill persons and have prevented serious incapacitation of people who otherwise would have become disabled. The above is not intended to be comprehensive. It does suggest that there has been some progress in preventing physical and mental disabilities and improving existing conditions.

Let us look at the debit side. The "Six Million Dollar Man" and the "Bionic Woman" in the television media present a sensational embodiment of the advances of science and technology. While these programs are dramatic in that they transcend the presently applicable and reach the still-to-be conquered areas, such programs in a sense suggest to the handicapped American people that television producers have paid more attention to the solution of problems for physically handicapping conditions than one sees in science and technology. In fact, if we were to look at the budgets of just these two programs, we might find them close to what is actually being invested directly in basic research in bioengineering in the area of physical disabilities.

Few recent bioengineering outcomes have benefited the disabled. Amputees have pretty much the same type of prostheses that they had twenty five years ago. Wheelchairs, from the point of view of the people who spend all of their waking time in them, have undergone little change. What little change that has taken place has occurred directly from suggested improvements to manufacturers by handicapped people. Science and technology have not been very much involved. Deaf people are still waiting for the availability of closed captioning devices for their home televisions that will unscramble a dot on the television screen, enabling them to read an ongoing line of captions. Deaf people and blind people would benefit from talking typewriters. Where deaf persons need to read in print the vocal productions of others, blind people need to hear the printed word.

Another dimension of the problem is the area of negative public attitudes toward the physically disabled. Physically disabled citizens have become experts in analyzing public attitudes. We are very much aware that it is a routine psychological reaction of people that causes them to avoid or move away from that which is perceived as different from their normal experience. When no improvement in the "different condition" occurs, no changes in attitude take place. Reduction in the handicapping effects of physical disabilities would enable greater and easier participation in day-to-day activities by disabled persons. The momentum from increased participation would product many spinoffs--one, at least, in improved public attitudes as "sameness" is enhanced and "differences" are reduced.

Citizens with disabilities are becoming increasingly more assertive in requesting a better level of commitment and responsiveness from federal, state, and local governments. Affirmative action and equal employment opportunities for the general population have been capitalized upon by handicapped consumers to meet some of their own needs. New evidence in the form of clauses in federal laws and in regulations governing these laws exists that directly provides for the participation of handicapped people in governmentally supported programs. However, physically handicapped citizens are learning quickly that there is a considerable difference between the promise of a law and actual delivery of programs. Progress in the last twenty years of governmental involvement in programs for the handicapped has been mostly in the form of expanding what were formerly sporadic pockets of services into national availability of these same services. More people now are getting what only a few were obtaining previously. Nothing very new, or very much improved from what was available previously, has been developed.

Government officials seem to be perplexed with the lack of satisfaction on the part of handicapped citizens. The ledgers of government agencies show large increases in dollar allocations and little reduction in citizens' complaints. Like many others in the mainstream of life in our nation, citizens with disabilities look to the government for solutions to their problems. Like other citizens, handicapped people have little understanding of or appreciation for the possible long-term benefits of basic research focused on the areas of physical disability. On the other side of the coin is perhaps a more complicated and difficult consideration: government agencies and the Congress also appear to underrate investments in basic research.

For consumers, the main concern is the need for consumer involvement in government employment and in participation in decision-making policies in programs affecting their welfare. They are less concerned with actually rank-ordering the priorities within the programs themselves. Typically, the complaints of handicapped consumers tend to be that program managers and professional workers lack sensitivity to the needs and desires of disabled citizens. Exactly what these needs and desires are, other than the desire to participate in formulating the programs, are often unstated or stated only in global terms. The end result, as stated above, is often an effort by the service delivery systems to expand services. Very little structuring of priorities based on carefully considered long-term objectives seems to happen.

More frequently consumers see changes occur as a result of political change in the leadership of a federal department. Broadly articulated department-wide focus results in a "reordering of priorities" within given agencies that hardly seem to be reprogrammed before another political change occurs. In the end, programs are neither understood, nor assessed on the basis of real needs; further, existing programs are not administered effectively. As a result consumer confidence in such programs is lost. Clearly, officials at the agency program management level of government have become too politically oriented and are expected to be too responsive to partisan politics to make the hard decisions necessary to improve the condition of handicapped citizens as well as should be done with the amount of dollars that do exist precisely for this purpose. In recent years, arbitrary and wholesale cancellation or curtailment of grant commitments by the vocational rehabilitation agency under the guise of unsatisfactory performance by grantee organizations is an example of loss of professional objectivity by government officers.

In this climate there is little appreciation for basic research. On the one hand, consumers with disabilities are no more sophisticated than most citizens when it comes to appreciating the long-term possibilities of basic research and on the other hand, basic research is not a politically attractive concept since the "payoffs" are unclear at the time of investment and "too far off" to meet the "immediate needs" of people clamoring for services.

Given these circumstances, it seems appropriate to consumer leadership that individuals and organizational leadership from science and technology could well make an important contribution by helping consumers to identify and prioritize programs, especially research programs, in order that a more effective and orderly approach can commence.

There is considerable confusion regarding research in both the vocational rehabilitation and education programs. In vocational rehabilitation, research allocations have been reduced by the Congress. More importantly, science and technology is insignificantly involved in use of the proportion of research dollars available. Most vocational rehabilitation research funds are awarded to applied research projects that are carried out by individuals from within the vocational rehabilitation profession. Research in education of the handicapped has generally been of poo quality. The new Institute for Education Research established a few years ago has yet to demonstrate any effectiveness whatsoever as far as handicapped consumers are concerned. The results and even the promise are still quite blurred. Science and technology from outside of the vocational rehabilitation and education fields is seldom involved and too seldom do leaders attempt to become involved. To consumers, the concept of science and technology conveys a picture of highly trained minds, with a decided distaste for politics and bureaucracy, working in laboratories that are far removed from governmental decision-making processes. If this picture is accurate then the dramatic reordering of priorities that is necessary is not apt to occur.

To delimit this general treatment of consumer perspectives some comments on the field of deafness follow to provide greater elaboration within a given disability area. A look at the field of hearing impairment will uncover possible opportunities that could be utilized by science and technology. Both the Rehabilitation Services Administration (RSA) and the Bureau of Education for the Handicapped (BEH) are authorized by legislation to conduct activities in the area of telecommunications. In RSA, this is a new authority that has not been utilized in behalf of deaf people. In BEH, this authority has been utilized largely to develop television captioning experimentation using existing technology. The National Bureau of Standards has been helpful in the television captioning effort. Neither RSA nor BEH has invested in basic research to directly explore the potential of devices, portable and otherwise, that will assist deaf people in overcoming receptive spoken communication problems. Organizations such as the National Association of the Deaf, the Alexander Graham Bell Association, the Conference of Executives of American Schools for the Deaf, and the Conference of American Instructors of the Deaf represent opportunities to conduct needs assessment and to identify areas of potential basic research activity. More important, these organizations, properly organized, can constitute an important political force for instituting a higher order of priority for research within the government once needs are clarified. Institutions of higher learning such as Gallaudet College, the National Technical Institute for the Deaf, and New York University could provide important and substantial resources for collaboration on basic deafness research activities.

Worthy of mention are two important basic research activities now under way. One consists of experimental implantations in the inner ear of devices that can be wired to computers involving neural stimulation and recognition of sound. This is being conducted in the Los Angeles, California area at the Ear Research Institute by Howard House, M.D. and William House, M.D.,* who are otologists. Bioengineers in Salt Lake City, Utah are also involved in this and similar research. A second basic research experiment involves the development of a speech-stimulated electronic cuer that focuses on providing deaf wearers with electronic cues which when combined with their visual perception of the speaker's lip movements will provide sufficient information to make visually perceived speech comprehensible.

Thus, audiological and speech considerations tend to be emphasized in research within the field of hearing impairment. Deaf consumers are concerned that this represents an overemphasis on attempting to strengthen what is weak or largely absent at the expense of attention to the many other areas of human function that are intact within deaf people and possibly of potential for new utilization in circumscribing the basic problem areas. While skepticism exists on the part of deaf people, for any given basic research activity, professionals in the field of deafness and deaf people themselves have never really had an opportunity to sit down with representatives

*Ear Research Institute, 256 South Lake Street, Los Angeles, California 90057, Dr. Howard House, President.

from science and technology to consider potentially fruitful areas of research activity, or to learn first hand what new technologies might be adapted to meet certain specific needs. For instance, deaf people have taken it upon themselves to develop a coupler enabling telephone communication to occur using teletype machines through regular telephone lines. This adaptation commenced in the late 1960's. The simple technology combined with the availability of thousands of obsolete teletype machines in the private sector have existed since the early 1950's. While this is a simple example of technology utilization, the point of importance is that no assistance was rendered from the scientific community that long possessed the expertise to effect this development.

Institutional and organizational capabilities within the field of hearing impairment do exist and can combine with science and technology in ordering and conducting basic research. A publication, Research on Behavioral Aspects of Deafness,* constitutes mostly a description of studies conducted by educators and psychologists from within the field of deafness. These research results do provide new information and new understandings of deafness and deaf people. However, within-field concentration does not yield the kind of dramatic breakthroughs that surely should result as general and specific advances of science and technology occur.

A movement in handicapped consumer activism has been underway at an accelerated pace in recent years. This activism, properly channeled, can also provide much needed direction. Consumer leaders would welcome input from the scientific community.

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CRITICAL ISSUES FACING THE HEALTH CARE SYSTEM

by

Charles C. Edwards, M.D.*

Senior Vice President
Research & Scientific Affairs
Becton, Dickinson and Company
Rutherford, New Jersey

*Dr. Edwards was Assistant Secretary for Health from 1973-1975 and Commissioner of the Food and Drug Administration from 1969-1973

In the following articles I discuss certain organizational issues in the health care system that I feel we must deal with if the system is to survive in anything resembling its present form. I believe these issues are relevant to the problems of the handicapped because if rehabilitation is to receive its appropriate recognition—both financially and organizationally—it must be fully integrated into the health system. Once rehabilitation becomes a full participant in the system, then the fundamental issues of organization, financing, research, and manpower become also the problems of rehabilitation.

I recognize the problems involved in fully integrating rehabilitation into our health care system. The traditional biases will make this a difficult but necessary undertaking if the problems are to be resolved.

RATIONAL CHANGE IN THE HEALTH CARE SYSTEM

Predicting the future is a perilous business. Even the most careful and thorough analyses have a way of missing the mark to one degree or another. And when the subject of such analyses and predictions is the American health care system, I would have to say that many of us in both the public and the private sectors have been guilty of some serious and costly miscalculations in the fairly recent past.

Certainly the architects of Medicare and Medicaid failed to anticipate the effect that these programs would have on the economics of health care, just as those who advocated massive spending for biomedical research and for the development of health manpower seem to have overestimated the effect these endeavors would have on the effectiveness and availability of health care.

Nonetheless, I think the Arthur D. Little study that forms the background for this Forum has provided some valuable insights about likely future trends in health economics and the health care marketplace. It is certainly obvious that the adoption of one or another form of national health care financing, whether comprehensive in scope or limited to so-called catastrophic coverage, would have profound effects on the economics of the health care system and the allied industries.

It is not my purpose this morning to critique the A.D. Little study, though I would offer one general comment: there is, I believe, an unstated underlying assumption here that the health care system of the United States is likely to remain about as we find it today, whether or not a system of national health insurance is put in place. That assumption, in my judgment, is open to serious question. For it seems to me that we are headed toward fundamental change in the structure and regulation of the health care system. The only unknown is the form that change will take and the means by which it is brought about. That is the issue I would like to raise for your consideration.

As to why I think fundamental change is certain to occur--and probably sooner than many people expect--the reason is simple. The United States, I think, has reached the point at which the cost of health care and the cost of developing the resources that make health care possible is becoming prohibitive.

Remarks by Charles C. Edwards, M.D.
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author.

This year alone, expenditures relating to health care will equal some $135 billion, which is well over $600 for every man, woman, and child in the country. We now commit at least 8.3 percent of our gross national product to health, compared with 5.9 percent ten years ago. Thus, not only is the cost of health care subject to staggering inflation, but in order to meet these costs we are diverting money from other sectors of the economy--from manufacturing, housing, transportation, education, agriculture or other activities that, in effect, are being curtailed in order to meet rising health costs.

Moreover, price inflation in the health field is having a more dramatic effect in the public sector than in the private sector. Overall health costs rose by nearly 14 percent last year. Public health spending, however, rose not by 14, but by 22 percent, to a level of nearly $50 billion.

There is no reason to anticipate a downturn in the cost of health care. On the contrary, some authorities are predicting not only continued inflation at or near the present rate, but a further shift in the GNP health component to 10 percent or more.

I do not believe the United States can afford this state of affairs. When the President feels obliged to ask for a lowering of the Federal share of the cost of Medicare in order to control spending--when many health insurance carriers are seeking rate increases of 30 to 60 percent merely to cover rising costs--when municipal and state governments are being forced to curtail health programs for the poor because they cannot afford to maintain them at former levels--when these things are happening, then one would have to be extraordinarily sanguine not to think that the system, as we know it, is in very serious trouble.

It seems to me, therefore, that we are faced with two options: either to do nothing meaningful and allow the health care system to remain on its present economic course toward collapse, followed by nationalization as the only way to assure that essential health services would continue to be available, or we can accept the urgent need for strong central regulation both to control costs and to make sure that the system will be fully responsive to public needs. In the absence of such regulation there seems little doubt that the adoption of national health insurance would hasten, rather than prevent, the collapse of the system. Thus, if we reject the option of regulation, we invite the far more extreme form of Federal domination that would inevitably come with the economic collapse and the resulting nationalization of the system. I want to return to this point in a moment.

As I have suggested on other occasions, I believe we need to take steps now to create a National Health Authority, a regulatory structure and system somewhat analogous to the Federal Reserve System, to provide for the health field much the same kind of central regulation that the Federal Reserve provides, in the public interest, for the banking industry. Let me hasten to point out that this analogy is not meant to imply that the banking system and the health system are cut from the same cloth. Obviously, they are not. The

point is that the Federal Reserve System and the members of the Federal Reserve Board are, by design, essentially apolitical. Unlike other key regulatory officials, such as the Commissioner of Food and Drugs for example, they do not serve at the pleasure of the President. Nor is the Federal Reserve System regularly given new and changing Congressional mandates through the budgetary or law-making process. Its purpose and functions are clear-cut; its authority is well-defined; and its actions gauged not by their political expediency or acceptability, but by their over-all contribution to the successful workings of the banking system.

Nothing less will serve in the health field.

Without any attempt to be exhaustive or detailed, I would suggest that a National Health Authority should be empowered by the Congress to establish rate and fee schedules on a regional basis, to approve or reject regional plans for the allocation of health resources, to determine health manpower requirements and see that they are being met, to regulate all public and private health insurance programs, and to advise the Congress and the Executive Branch on budget and policy issues. And obviously, a National Health Authority would have to be granted sufficient powers and sanctions to make its decisions binding.

As a purely regulatory body, a National Health Authority would in no way supplant or reduce the need for the health activities of the Department of Health, Education, and Welfare or of a Department of Health if one were created. The service and funding activities of HEW and the regulatory activities of a National Health Authority would be entirely separate, as indeed they should be. It seems to me that one of the most serious mistakes in public administration is to create an organization with a clear purpose and then hobble it by adding more functions and more responsibilities that go well beyond its original mandate. The Social Security System is a prime example of an agency and a program that are in very serious financial trouble partly because we have burdened them with functions such as monitoring the quality of medical care, determining whether a kidney disease treatment facility should or should not be eligible for Medicare reimbursement, and numerous other functions that stretch the original concept of old age and survivors insurance far beyond its original intent. So I would emphasize that, to be effective, a National Health Authority would have to confine itself to central regulation of the health care system and leave the non-regulatory, service functions to the agencies of government that have been created to carry them out.

I understand, of course, that there is a growing disenchantment with the Federal Government and with Federal regulation, and that the idea of establishing a National Health Authority is, to a degree, out of step with the times. Furthermore, I can readily appreciate the opposition to such a proposal that would come from within the health sector and from the Congress. Just as the medical profession, for example, is strenuously opposed to any and all forms of government control of the practice of medicine, so too does the Congress jealously guard its prerogative to deal with health and other social issues through the legislative process. Yet it is abundantly clear that neither the private health sector nor the Congress--nor for that matter the Executive Branch--has demonstrated

the capacity for leadership that is so patently lacking on the American health scene. Neither have they shown the ability to either recognize or to work together in the face of a deepening economic crisis the outcome of which can only be disastrous for the health care system and for the people it serves.

The approach I am suggesting will require that the medical profession accept some trade-offs in order to preserve its essential independence. In exchange for the opportunity to remain a viable private institution in society, medicine will have to accept a measure of regulation greater perhaps than it is used to, but far less than would be necessary under a nationalized health care system. By the same token, the Congress would have to consent to less day-to-day manipulation of health policy and national goals. With all due respect to the legislative process and to the right of the American people to a voice in issues that directly and vitally effect their lives, I think it is self-evident that piecemeal legislation is not the way to deal with the major problems confronting the health care system--its overwhelming economic problems, its problems of quality, of access, or of effectiveness of health care.

Since we are chiefly concerned here with examining the impact of economic trends on the health care system and the industries that relate to it, let me mention one additional point that I think is germane.

It has been suggested to me that strong central regulation of the health field will not work for the same reason that the U. S. Postal Service is in such extreme financial difficulties, namely that the Federal Government is a poor manager of complex industries. I hope that I have made it clear that I am not suggesting that the Federal Government run the health care system. Indeed, that is the very thing I believe a National Health Authority could help avoid. What I am suggesting is that there is an urgent need for central regulation, not for a Federal takeover of the system.

There is also, of course, a strong conviction that regulation would be economically stifling for the health care industry. In reply I would just point out that some of the best examples of highly successful and profitable segments of American industry are to be found among those subject to Federal regulation. Obviously, a health regulatory process would have to assure the continued viability of the health care system; otherwise regulation would defeat its own purpose. That is undoubtedly a difficult challenge. Yet I am convinced that without regulation the health care system and the industrial groups that serve it will shortly see the end of profitability because the U. S. economy will not be able to sustain them.

In summary then, I am convinced that dramatic change is coming in the American health care system, and that we are now faced with the responsibility to see to it that change is rational and creative, rather than chaotic and destructive. Unchecked economic forces are operating in and on the health field that can only lead to its collapse. No health insurance proposal currently under consideration offers any real prospect for a reversal of trends that, I believe, signal financial ruin on a scale that dwarfs the problems of New York City. If national health insurance is to be imposed

on the present health care system--and I firmly believe that the country needs and should have national health insurance--then it is absolutely necessary that we put in place a mechanism for strong central regulation of the entire health care system. In that way, private enterprise can continue to serve the public interest at a price that the American people can afford to pay.

Realistically, we have no other option.

SOUNDING BOARD

Form and Function in the Federal Health Effort

In March, 1975, shortly after leaving the post of Assistant Secretary for Health, I offered some observations on the federal health effort in an article appearing in the Journal (N Engl. J. Med. 292:559-562, 1975). At that time, I raised the question whether the leadership in either the public or the private health sector was in a position to influence the making of national health policy in the face of political pressures being exerted by the Congress and the White House, neither of which, in my view, is equipped to make sound judgments without expert guidance from the health enterprise. My office had sought to provide that guidance by the preparation of a Forward Plan for Health, a document developed through a comprehensive and continuing management-planning process within the Public Health Service and the Office of the Assistant Secretary for Health.

The first Forward Plan was distributed in the summer of 1974. The second was published in August, 1975, and the third probably will be issued at about the same time this year. If past experience is a reliable guide, this year's Forward Plan, like the first and second, will be turned aside by Congressional and Executive Branch policy makers, and its analyses and recommendations of major health-policy issues will be disregarded. In short, a careful, thorough, rational and apolitical treatise on the health problems of the nation and the respective contributions that the public and the private sectors can make toward solving those problems will be buried in the scramble to get the biggest political bang from the federal health dollar.

I think, therefore, that those who are concerned about the development of national health policy may want to consider what changes within the federal health structure might contribute to a reduction in politically inspired decision making and to the acceptance of rational planning as the basis for health-policy decision.

It seems fair to say that government's function in the pluralistic health enterprise remains unclear and controversial. For political reasons made all the more evident in a presidential election year, and for philosophical reasons that reflect a traditional conflict between attitudes and motives in the private and the public sectors, the nation has yet to come to terms with the question of the government's basic function (or functions) within the health system. Although there can be no doubt that the federal government dominates the making of policy in every facet of the system, no endeavor in which the government occupies so powerful and dominant a role

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is as unplanned, uncoordinated, and unguided as the federal health effort. Unless this condition changes--unless the function of the federal health effort and the form to carry out that function can be defined and established in an atmosphere unhindered by political bias and philosophical cant--I submit that the system as it is now known is headed for collapse and that in its place a system completely under the control of the government will be erected.

As the first step in this restructuring, I believe that two of the prime functions of the federal health program--namely, regulation and program management and support (encompassing research and development, training, construction, community assistance, state aid, the provision and financing of health services, efforts to improve the quality and availability of health services, etc.)--must be separated. Regulation and program management are inherently different functions having different goals and perspectives. To group these functions, however loosely, within the Department of Health, Education, and Welfare, which is itself a loose confederation of programs and functions held together more out of tradition than logic, serves only to compound the problem of management. It is illogical and impractical to assign to the same group of managers the responsibility to support the development of health resources and the provision of health services together with the frequently conflicting responsibility for regulating ever more numerous facets and functions of the health-care system. Moreover, to lodge these disparate responsibilities with a department that is extraordinarily subject to political pressures (primarily because its constituency is literally the whole population) is to invite the very political domination that has in recent years severely hampered the Department's health leaders in providing influential leadership.

The federal health effort should be realigned under three separate structures: an agency, perhaps a cabinet-level Department of Health, that would continue the management and support functions mentioned earlier; a regulatory agency much like the present Food and Drug Administration, concerned with the safety and effectiveness of products whose use bears directly on health and health care; and a separate regulatory agency empowered to control health-care costs. The first two of these functions are firmly established; the third does not yet exist despite the fact that essentially uncontrolled growth in health spending and health-care prices threatens the vitality of the entire system and is the major force impelling the development of national health policy. The federal government can and should control the market for health services, and such control, divorced from the need to accommodate political interest, is essential to the preservation of a private-sector component in the American health-care system.

I propose the creation of a National Health Authority--the precise name is unimportant--whose function and responsibility would provide the regulation necessary to maintain economic stability in the health system. Such an Authority would be composed of a small number of persons nominated by the President and subject to confirmation by the Senate who would serve staggered terms of not less than six years as full-time members of the Authority. Constituted in this way, the Authority would be substantially

removed from the day-to-day political struggle that exists within the Executive Department and, although it may have some legitimacy there, is totally inappropriate in a regulatory activity.

In broad terms, the Authority would have the statutory power to promulgate guidelines under which regional bodies, such as the state and local planning agencies being established under the Comprehensive Health Planning and Resources Development Act (PL 93-641), would adopt regional rate and fee schedules as an integral part of their planning function. These schedules would in turn be reviewed and approved by the National Health Authority, and once approved they would be applicable to all federally aided health-care activities and institutions within the jurisdiction of the planning agency. In developing guidelines, the National Health Authority would seek not necessarily national uniformity in the pricing of health services, but rather national consistency in the criteria by which prices are arrived at and in the determination of what constitutes a rational balance of health resources and expenditures. The National Health Authority would work toward narrowing the gap between the index of health prices and the general cost-of-living index, there being no logical reason for health costs to increase at as much as five times the rise in the cost of living, as happened in the first quarter of this year.

Initially, the regulatory powers of a National Health Authority would be confined to existing federally aided health-care programs, chiefly Medicare and Medicaid. But the adoption of a system of a national health-care financing covering the entire population and paid for, at least in part, through tax revenues would extend the jurisdiction of the National Health Authority virtually to the total health-care marketplace. It could serve, in fact, to create the incentives for cost containment that are the objectives of limited experiments and demonstrations being carried out under existing legal authority. Although such cost-containment projects are useful and possibly instructive, they can hardly be expected to gain the upper hand on inflation within any acceptable period. They come too late, and they will take too long to demonstrate their usefulness. The need for rational regulation of the health-care marketplace is urgent, and although experimentation is warranted, the nation cannot afford to defer action to contain costs. In fact, it seems quite clear that any system of national health insurance that might be adopted could only reach its objectives if it incorporated regulation of health-care cost. For without such regulation, the increased demand for health services resulting from national health-care financing would almost certainly bankrupt the system and hasten the move toward federalization of the American health enterprise.

In proposing economic regulation of the health-care marketplace and the creation of the National Health Authority to carry out this function, I fully appreciate the genuine concerns of many physicians that such regulation would seriously compromise their ability to meet the needs of their patients. Economic regulation could quite possibly impose constraints on a physician's freedom to choose any diagnostic or treatment course available. The applicable economic controls adopted for a physician's region may in fact preclude reimbursement for certain procedures under certain circumstances. Ideally, of course, such decisions, having been arrived at

by competent health-planning agencies in co-operation with Professional Standards Review Organizations and similar professional review bodies, would reflect the best judgment of one's colleagues. But even that would still leave regulation an unpalatable intrusion in the view of some members of the profession. Such sentiments are not to be taken lightly. They stem from a long tradition of professional independence that has undoubtedly contributed to progress in patient care. But it is also true that the medical profession cannot reject the economic realities of the times and of the system within which they work. Failure to control costs will lead to the collapse of the system. Facing a clear and present danger and having the capability to address that danger through the judicious use of tools and resources that are either in place now or shortly will be, the medical profession has no reasonable choice other than to accept economic regulation, not only to control inflation but also to preserve the health-care system itself.

In my judgment, economic regulation is an essential, as yet unmet, responsibility of the federal health enterprise. In that such regulation must be imposed throughout the nation in accordance with national guidelines that must be applied regionally with equity and consistency, there seems to be no other component of the health-care system capable of carrying out this function. But if regulation is to work fairly and effectively, it will have to be managed by a component of the federal health enterprise that is by design insulated from political tampering to a degree that the Department of Health, Education, and Welfare or even a Department of Health neither could nor should be. For that reason, I firmly believe that the National Health Authority must be organizationally separate from both the agency responsible for support of the health system and the agency charged with regulation of drugs, devices and other health-care-related products. This rearrangement of the form of the federal health effort along lines dictated by functional responsibilities is a critical next step toward bringing order to the federal health enterprise and stability to the national health system.

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